

THE PERCEIVED IMPACT OF A RELATIVE'S MENTAL ILLNESS ON  
THE FAMILY MEMBERS, THEIR REPORTED COPING STRATEGIES  
AND NEEDS: A ZIMBABWEAN STUDY

BY

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# ABSTRACT

**Background:** Mental health service resources are inadequate in low income countries, and families are frequently expected to provide care for people with mental illness. Research on the consequences of caring for mentally ill relatives has been limited especially in low income countries.

**Aim of the study:** To explore the perceived impact of mental illness, reported coping strategies and reported needs of family members of mentally ill patients attending the Parirenyatwa Annexe Psychiatry Unit in Harare, Zimbabwe.

**Setting:** Annexe Psychiatry Unit in Harare, Zimbabwe.

**Methods:** A purposive sample of 31 family members, who were primary caregivers, attending Psychiatry Unit in Harare Zimbabwe, participated in nine in-depth interviews and three focus group discussions using standardized study guides and were also screened for Common Mental Disorders using the 14 item Shona Symptom questionnaire (SSQ). Qualitative data were entered into the NVivo 8 software package and analysed thematically. Statistical Package for Social Sciences (SPSS version 16) was used for quantitative data analysis. Pearson correlation test for association was conducted at a significance level of  $\alpha = 0.05$ .

**Results:** Thirty one family caregivers participated in the study. The mean age was 44years. Twenty one (68%) were female with 11(35%) being mothers of the patients. Twenty (65%) were married, 18(68%) lived in high density suburbs, 23 (68%) were unemployed and 97% belonged to some religion. Family member caregivers experienced physical, psychological, emotional, social and financial burden as well as stigma associated with caring for a mentally ill relative. Both emotion focused and problem focused coping strategies were used by family members. Seeking spiritual assistance emerged as the most commonly used way of coping. More than two thirds (68%) of the caregivers were at risk of Common Mental Disorder

(CMD) with 32.3% being at risk of severe CMD and these were referred to the Psychiatrist for further management. There was a significant positive association between gender and CMD ( $p=0.023$ ).

**Conclusion:** Family caregivers carry a substantial and frequently unrecognized burden as a result of the mental illness of their family members. Better support is needed from health professionals and the Government to help them cope better. Further research is needed to quantitatively measure caregiver burden and to evaluate potential interventions in Zimbabwe.

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## **DEDICATION**

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## **List of Abbreviations**

CMD	Common Mental Disorder
FGDR (1-11)	Focus Group Discussions Respondents (1 to 11)
HIC	High Income Countries
LMIC	Low and Middle-Income Countries
R1- R 9	Respondent 1 to 9
SSQ	Shona Symptom Questionnaire
WHO	World Health Organization

# **CHAPTER 1**

## **BACKGROUND OF THE STUDY**

### **1.0 INTRODUCTION**

In low and middle-income countries (LMIC), mental health services are scarce, cover a small proportion of the population and face chronic shortages of financial and human resources (WHO Atlas, 2011). There are an estimated 0.05 psychiatrists per 100 000 population in low income countries, 2.57 per 100 000 population in middle income countries and 8.59 per 100 000 population in high income countries (HIC), with similar trends for psychologists and nurses (WHO Atlas, 2011). The estimated overall shortage of mental health workers is 17.3 per 100 000 population in low-income countries and 14.9 per 100 000 population in middle-income countries (WHO Atlas, 2011).

Zimbabwe follows the trend in many other low-income countries, with major deficits in mental health services (Ministry of Health and Child Welfare, 2012). The number of psychiatrists is estimated to be 0.06 per 100000, psychologists 0.04 per 100 000 and nurses 2.86 per 100 000 population. Admission to mental hospitals is at the rate of 11.99 per 100 000 whilst admission to psychiatry beds in general hospitals is at the rate of 7.39 per 100 000 population (WHO Atlas, 2011).

Historically, formal mental health services in Zimbabwe began with the establishment of the first asylum now called Ingutsheni Hospital, in 1908 in Bulawayo, Southern Rhodesia (Jackson, 1999). This asylum initially housed 20 Africans and 10 Europeans but later between 1917 and 1924 was expanded as the numbers of inmates continued to increase (Jackson, 1999). In 1933 the medical superintendent of the asylum requested the magistrates to stop sending “lunatics” to the asylum as there was overcrowding. The asylum was later turned into a mental hospital in 1933 following the worldwide discrediting of asylums on humanitarian grounds (Jackson, 1999). This mental hospital was adversely

affected by the shortage of human and material resources that occurred as a result of World War 2. Decentralization of psychiatry services then began in 1969 when some of the patients were transferred to Ngomahuru hospital in Fort Victoria (now called Masvingo) for long term care and a 60 bedded ward was established in Salisbury (now called Harare). The increase in the number of patients and the shortage of human resources, led to the establishment of a post basic psychiatry course for nurses in 1970. A period of de-institutionalization followed, with the establishment of follow up care in the community as nurses trained in psychiatry were placed in the community to provide psychiatric care (Jackson, 2005).

After attaining independence in 1980, Zimbabwe adopted the concept of decentralization of public health services to local government like many other low-income countries (Todd et al., 2009). This arose from the perception that services planned in consideration of local needs were likely to better address those needs. However, this initiative failed due to inadequate financial and human resources for mental health (Todd et al., 2009). In 1987 mental health was incorporated into primary health care, following the principles of the Alma Ata Declaration. Since then most mental health patients are managed in community settings, but services continue to be affected by inadequate resources (Ministry of Health and Child Welfare, 2005).

In many HIC, there have been continuous efforts since the 1950s to reduce the length of hospital stay and increase treatment in the community for people with psychiatric disorders (Stern, 1999). The shift from hospital care to community care has been driven by a number of factors. First, the human rights movements in the 1950s and 1960s led to concerns about human rights violations in asylums, which had become the custodial institutions for many people with mental illness (Stern, 1999; Thornicroft & Tansella, 1999). Secondly, innovations in psychotropic medications have allowed people with mental disorders to function relatively well and live near normal lives in the community hence the shift to community care (Thornicroft & Tansella, 1999; Ohaeri, 2001). Thirdly, efforts to reduce costs by health care providers have also played a pivotal role in the down scaling of psychiatric hospitals (WHO,

2003). In most HIC there was de-institutionalization which was unfortunately not followed by the development of appropriate community services because of lack of resources (Thornicroft & Tansella, 1999).

Whether due to the lack of mental health service resources in LMIC, or the history of deinstitutionalization in many HIC, the burden of care for people with severe mental illness frequently falls on family members and the communities in which they live (Hsiao et al, 2006; Saunders, 2003; Yip, 2004). According to the World Health Organization (2003), at least one in every four families in the world has a member with a mental or behavioural disorder.

Members of a family have different roles to play within the family in everyday life and members tend to complement each other in terms of roles. Traditionally, gender roles are very clearly defined in such a way that the father is the sole breadwinner whilst the mother looks after the children at home ensuring that they go to school as well as teaching them life skills (Yip, 2003). Results from studies on care giving among Chinese families have shown that female family members are usually expected to be the primary caregivers for general health needs and to accomplish a number of tasks for other family members (Chou et al., 1999; Chien & Norman, 2003).

Mental illness is generally viewed by communities as a family problem rather than a societal problem (Lauber & Rossler, 2007; Yang, 2007; Yip, 2003). Family members may be called upon to provide care giving roles that depend on which member of the family is mentally ill. There are particular challenges within families where parents are mentally ill and are unable to support their families (Yip, 2003).

Burden has been defined by Grand and Salisbury (1966) as the negative impact on the family caused by caring for an ill member. Caregiver burden commonly refers to the psychological, physical, emotional, social and financial challenges faced by family members caring for a mentally ill relative (Given et al., 1992; Chou, 2000). Burden may be described as either subjective or objective and caregivers may experience both (Platt, 1985; Hoeing &



Hamilton, 1966). Subjective burden is defined by Platt (1985) as the psychological consequences of the family, such as the family members' appraisal of the situation and the perceived severity of their burden. Objective burden refers to the objectively measurable demands placed on the family members, which includes disruption of daily routine, leisure time, finances, reduction in social support as well as physical and verbal aggression of the patient (Grad & Sainsbury, 1966).

The extent of the burden of mental illness on family members is difficult to assess and quantify and partly as a result of this, is frequently ignored. However, according to the World Health Organization (2003) it has a significant impact on the family's quality of life. The majority of individuals who are hospitalized due to mental health problems either live with or have contact with their families after being discharged from the hospital (Schwartz & Gidron, 2002; Yip, 2004; Zauszniewski et al, 2009). Most of these individuals rely on their families for care and support throughout their lives (Fujino & Okamura, 2009; Moller et al, 2009; Zauszniewski et al., 2009).

There is growing evidence from around the world that families are scantily supported to provide care required by their family members with mental illness and struggle to provide this support (eg. Doornbos, 2002; Magliano et al., 2005; Yip, 2003). This is because of community attitudes and beliefs which frequently have an effect on the type of assistance provided to families of individuals with mental illness (Marsh, 1999; Yang, 2007).

Families provide long-term assistance with housing, financial support and rehabilitation to their mentally challenged family members (Marsh & Johnson, 1997; Solomon et al, 1996; Sun & Cheng, 1997). They are also expected to take up a variety of roles which include being a family caregiver, an informal case manager as well as managers in a crisis (Doornbos, 2002; Magliano et al., 2005; Yip, 2003).

Individuals with severe mental illness have physical, financial and psychological implications for families comparable to that of persons with other illnesses such as Alzheimer's disease

or cancer (Mays, 1999). In the United States of America (USA) estimates have shown that between one and two thirds of persons with long term psychiatric disabilities are taken care of by their families (Dyck et al, 1999). Data from the same country shows that 40% of patients with schizophrenia live with their relatives while in China more than 90% of people with this condition live with their families (WHO, 2005).

A study conducted across Europe by Schuize & Beate (2005) revealed that caregiver burden in schizophrenia was high across England, Denmark, the Netherlands, Italy and Spain. Caregiver burden was higher when caregivers lived with the patient (Schuize & Beate, 2005). A report called Worried, Tired and Alone (Mays et al., 1999) reports the results of a survey which set out to analyze issues affecting caregivers in Western Australia the results which revealed that the majority of caregivers experienced personal, emotional and physical strain on their lives as well as the loss of personal freedom as a result of caring for a mentally ill relative.

Although much of the research on family caregiver burden has been conducted in HIC settings, similar findings are evident in southern Africa. In a qualitative study conducted among 36 family members of mentally ill patients in Botswana by Seloilwe (2006), findings revealed that family members had become the primary source of psychological support and that they perceived the situation as burdensome because of inadequate resources. The families, ill relatives and the health professionals were frequently required to negotiate about the care of the patients.

There has been a shift from health care previously provided by health professionals in the hospitals to community mental health care in Botswana (Seloilwe, 2006). Though community care requires teamwork and partnership, families often become discouraged, stuck, overburdened, and fatigued by the care of their relatives and end up failing to form the partnership and teamwork (Hartfield & Lefley, 1987). Botswana established their first Psychiatry institution in 1938 (Seloilwe, 2006). After the observation that their only psychiatry

institution had become overcrowded, as the number of patients exceeded the bed capacity, there was a shift from hospital care back to community care and families again became responsible for the care of their relatives (Seloilwe, 2006). This supported similar findings by Chamber et al (2001) in their study in the same country the results which revealed that the families had become pivotal to the care of their ill relatives as a result of this shift from institutional care to community care.

## **1.1 RATIONALE FOR THE STUDY**

The rationale for this study is based on the following three arguments.

### **1.1.1 High burden on family members**

In Zimbabwe, as indicated above, a shift in responsibility from hospital care to community care has occurred, largely due to the limited psychiatry care resources. This includes the lack of facilities, such as the limited beds to accommodate patients in need of admission, as well as a deficit in human resources to sustain these services (Ministry of Health and Child Welfare, 2012). The Zimbabwean health system is affected by a substantial shortage of skilled and experienced health workers which endangers the important health gains that Zimbabwe achieved in the past (Ministry of Health and Child Welfare, 2012). The health system currently operates at 57% of staffing capacity (Zimbabwe Health System Assessment, 2010 p 71). This shortage of human and material resources has limited the sustainability and coverage of mental health care programmes (WHO Mental Health Atlas, 2011). Access to available mental health services is generally centralized and not easily accessible to the majority of people especially those in rural areas (Mudzingwa, 2007). This has resulted in families frequently taking care of their ill relatives.

### **1.1.2 Lack of support for families at Annexe Psychiatry Institution in Zimbabwe**

Due to shortage of human resources and pressure of work at Annexe Psychiatry Unit in Harare Zimbabwe, clinical observations and discussions with the clinical staff have shown

that there is limited psychosocial support that is given to relatives of mentally ill patients. This is a concern as the family members are the primary source of care for patients in the community and therefore need to be mentally and physically well to effectively provide care to their mentally ill relatives.

### 1.1.3 Lack of research

Research on the impact of mental illness on families in Zimbabwe has been intermittent and emphasis has largely been on the patient's illness, for example (Abas & Broadhead, 1997; Patel, Abas, Broadhead & Todd, 2001). Currently there are no reliable and valid data on the consequences of mental illness for family members in Zimbabwe. Only two studies that have explored the impact of mental illness on family members in Zimbabwe could be located. The first study, published in 1995 by Wintersteen et al found that families in Zimbabwe bore heavy responsibility for providing assistance for persons with mental illness and consequently required a great deal of support. This was a qualitative study with a sample that comprised of family members of patients with conditions that closely resembled schizophrenia and bipolar affective disorder who were known and identified by health professionals. These participants who were known by health professionals are likely to have had different characteristics from those who accompany patients to the hospital for review or admission. This study neither examined specific coping styles, nor explored caregiver burden in relation to specific conditions such as bipolar affective disorder or schizophrenia. The extent of the psychological impact was also not examined in the above study.

The second study was conducted by Nyati and Sebit in 2000. This was a community based descriptive cross sectional study on the burden of mental illness on caregivers, family members and the community. The study comprised of 66 caregivers and 126 patients who were randomly selected from rehabilitation centers, community day centers, resettlement villages in three provinces namely Harare, Bulawayo and Masvingo. The results revealed that family caregivers faced multiple problems but were more tolerant to the patients'

behaviour than the community. However, the study did not characterize the impact of mental illness or identify the needs, experiences, available resources and network support systems of families of mentally ill patients in Zimbabwe. The study also did not examine the common coping strategies of those family caregivers. These Zimbabwean studies did not examine the extent of the psychological and emotional impact of mental illness on the family members.

Much of the existing research on care giving in families living with mental illness has been conducted with families living in high income societies (Aschbrenner, 2009; Moller et al., 2009; Van Der Voort et al., 2007). The findings from these studies may not accurately reflect the experiences of families living in Zimbabwe.

## **1.2 Aim of study**

The aim of this study was to explore the perceived impact of mental illness, reported coping strategies and reported needs of family members of mentally ill patients attending the Annexe Psychiatry Unit inpatient and outpatient departments in Harare, Zimbabwe.

## **1.3 Objectives of the study**

1. To explore the perceived impact of mental illness on the family members when a relative is mentally ill.
2. To explore the strategies used by family members to cope with having a relative who is mentally ill.
3. To identify the reported needs of family members with a mentally ill relative.
4. To assess psychological distress among family members with a mentally ill relative, using the Shona Symptom Questionnaire (SSQ).

## **1.4 Research Questions**

1. What is the perceived impact of mental illness on family members when a relative is mentally ill?
2. What are the reported coping strategies used by family members when they have a mentally ill relative?
3. What are the reported needs of family members with a mentally ill relative?
4. What is the extent of psychological distress among family members when they have a mentally ill relative?

# **CHAPTER 2**

## **LITERATURE REVIEW**

### **2.0 Introduction**

A literature review assists the researcher to find out what already exists in relation to a problem of interest (Polit & Hungler, 1999). It helps the researcher to learn about the current state of knowledge with regards to a particular issue, as a means of improving practice or identifying potential solutions to a problem. A literature review also helps to identify gaps in existing knowledge and how a new study can potentially fill the gap.

This chapter reviews literature on the impact of mental illness on various aspects of the family which includes finances, social relationships, physical health and emotions. The effects of mental illness on family members are reviewed. Literature is also reviewed on how families cope with mental illness and how families believe they can be helped in order to cope effectively with a relative who has been diagnosed with a mental illness.

### **2.1 Search strategy**

The following databases were searched to identify studies for the review: Google Scholar, MEDLINE, Pub Med and HINARI. The following keywords were used: “care giving” OR “caregiver role” OR “family role” AND “mental illness” AND “coping”, AND “family” AND “mental illness”, “primary caregiver” OR “family caregivers” AND “mental illness”, as well as specific conditions such as care giving in schizophrenia, bipolar disorders and stigma associated with caring for a mentally ill family member. The other key words used were “gender” AND “care giving” OR “gender roles” AND “families” AND “mental illness”. The reference lists from the identified studies and review articles were searched for other relevant studies and these were downloaded and reviewed. In addition, specific journals such as the Community Mental Health Journal, Issues in Mental Health Nursing, Journal of

Family Nursing, Journal of Psychosocial Nursing and Mental Health Services, Psychiatric Services, and Central African Journal of Medicine were identified through hand search of the Table of Contents as they are available in the library at the University of Cape Town and the University of Zimbabwe. This was done from February to August 2012.

## **2.2 Inclusion/exclusion criteria**

Studies eligible for inclusion were those published in English between 1980 and 2012 on the subject of care giving and mental illness in any country among families of individuals with schizophrenia and bipolar affective disorder. Studies were selected if they included the impact of mental illness on the family, the family's coping strategies and the family's needs.

Studies were excluded if they focused on care giving of individuals with other chronic conditions and other psychiatric conditions other than bipolar affective disorder and schizophrenia. Those studies which were in other languages other than English were also excluded.

Both qualitative and quantitative studies were included.

## **2.3 Number of studies found and data extraction**

In total 4,854 global studies were found using the above search terms. After title and abstract review, 92 studies that met the inclusion criteria were found and full text articles were retrieved. The full text articles of all included studies were read, and themes were extracted qualitatively, informed by the major research questions of this study. These themes were:

1. Impact of mental illness (specifically bipolar affective disorder and schizophrenia) on the family (including effects of mental illness on family social relationships, leisure activities, physical health, safety and finances, as well as stigma associated with mental illness).



2. Coping strategies of family members with a schizophrenic or bipolar affective disorder patient.
3. Reported needs of families with a mentally ill relative.

**Table 1: Number of studies reviewed per theme globally**

<b>Study theme</b>	<b>Number of studies</b>
<b>1. Impact of mental illness</b>	
Physical impact	6
Psychological/ Emotional	3
Social	3
Stigma	13
Impact of Schizophrenia on the Family	15
Impact of Bipolar Affective Disorder on the Family	7
Gender and care giving	28
<b>2. Coping strategies</b>	
Emotion focused/ Problem focused	11
<b>3. Reported Needs</b>	6
<b>Total Number of Studies reviewed</b>	<b>92</b>

## **2.4 Impact of mental illness on the family**

Mental, neurological and substance use disorders make a substantial contribution to the global burden of disease (WHO, 2011). Neuropsychiatric conditions accounted for 14% of the global burden of diseases in 2010 with the common causes of health related disability worldwide being depression, schizophrenia, bipolar depression and dementia (WHO, 2011).

In the context of this enormous burden, it is frequently the responsibility of families to take care of those affected by mental illness. Family members have described the experience of

personal loss as a result of their loved one's mental illness as being as serious as losing them due to death (Macgregor, 1994). Interpersonal and psychological distress has been reported to be associated with higher levels of loss due to mental illness (Stein et al, 2005). Studies in HIC have revealed that personal loss attributed to mental illness includes changes in current roles and routine, self-identity and previous relationships (Stein & Wemmeru, 2001). Parents, spouses and siblings more often focus on the mentally ill relative and as a result are often unable to deal with their own individual or family developmental needs. Some studies in the USA have found a relationship between negative family environments and relapse (Holey & Campbell, 2002; Weisman et al., 2000) while only one study by King (2000) did not support those findings.

In another USA study that set out to examine the experiences of living with a family member with bipolar disorder, the findings showed that family members felt alone, struggled to make sense of their experiences, and found it difficult to maintain a sense of normality, as their life was encroached on by the effects of the condition (Jonsson et al., 2011). Numerous studies in Western countries have shown that family care causes stress, financial difficulties and depression (Wancata et al., 2006). This was also supported by findings of a review by Awad and Voruganti (2008) which showed that the relatives of the mentally ill patients experience physical illness, depression and anxiety.

#### 2.4.1 Effects of mental illness on family social relationships

Discrimination in the form of social avoidance has also been found to be a result of blame and shame by the extended family. Three large studies in the USA reported that about a fifth to a third of family members reported strained and distant relationships with extended family or friends or both because of a relative with mental illness (Oestman & Kjellin, 2002). However another study in the same country found a much smaller rate, with only 10% of a sample reporting occasional avoidance by a few people (Phelan et al., 1998). People living with mental illness have limited social networks and are more strongly linked to their families

and more dependent on them (Thornicroft, 2006). A limited social network may be a result of stigma or the mental disorder itself (Thornicroft, 2006). The associated loneliness and social isolation can become a risk factor for poor recovery (Thornicroft, 2006).

### 2.4.2 Stigma associated with mental illness

In many societies around the world, stigma is associated with mental illness (Thornicroft, 2006). Relationships with neighbours and the community at large can be strained. At times the family can be socially isolated due to the patients' behavior during the episode as some patients may become either physically or verbally aggressive (Struening et.al, 2001). This makes it difficult for neighbours to understand the condition. Studies in USA have also shown that 43% to 92% of caregivers of people with mental illness report having been stigmatized (Struening et.al, 2001) and that perceived stigma were associated with reports of depressive symptoms (Phelan et al, 1998).

Another study done in the USA, revealed that greater perceptions of stigma towards caregivers were associated with relatively higher levels of depressive symptoms and that stigma reduces the morale of the family members who help care for people with mental illness (Perlick et al, 2007). Embarrassment of the symptoms and behaviour of the patient often results in siblings and parents avoiding bringing others to the home (Brady, 2004; Gonzales et al, 2003).

Culturally defined stigma of mental illness among societies in China has often resulted in intense feelings of shame, guilt and humiliation, and in this particular context, the burden falls on the family rather than on the individual (Huang et al., 2008; Wong, 2000). This has resulted in other unwanted social effects, which include limited social life and reluctance to reach out for support from relatives, friends, neighbours and other health care providers in spite of difficulties in dealing with the patient's behavioural problems (Song, 1998). Families have also felt that discrimination against their mentally ill relative is also directed at them (Gonzales Torres et al., 2007). One study on mental illness stigma and discrimination in

Zambia revealed that stigma was caused by misunderstanding of mental illness etiology and the perceived dangerousness of people with mental illness (Kapungwe et al, 2010).

### 2.4.3 Effects of mental illness on income and finances

Household and work routines may be disrupted by mental illness of a loved one (Biegel & Schulz, 1999) and this can result in loss of productivity for the family unit (WHO, 1996). Family members are often required to pay for medical treatment for their loved one with a mental illness (Dyke et al, 1999). In a survey done in Tanzania by Whyte (1991), financial loss was reported by 26.5% of the participants with families spending large sums of money in payment of traditional healers.

In a cross sectional study, Osayi et al (2010) interviewed a sample of 200 caregivers of people with schizophrenia in Midwest Nigeria using the Burden Questionnaire (BQ). Findings indicated that the mean financial score was significantly higher than the mean scores for burden of family routine disruption, social stigma, interaction and subjective distress. In the same study, caregivers of unemployed patients were found to have higher burden than caregivers of employed patients and the level of burden was associated with caregivers' educational level and age of the patient. According to the authors, this was because the relatives had to bear the cost of looking after the patient and the cost of mental health services out of their pockets with no assistance from the patient (Osayi et al. 2010).

### 2.4.4 Emotional Impact of mental illness on the family

Caregivers may be overwhelmed by lack of social support from friends, family and treatment providers resulting in the family members feeling isolated and restricted from pursuing their own activities (Biegel & Schulz, 1999). Guilt and loss (WHO, 2005), helplessness, fear and vulnerability (Stern, 1999), and cumulative feelings of anxiety, resentment and anger are emotions which are often reported by caregivers (Dyck et al, 1999). Frustration in making sure that the patient takes their medication (Biegel & Schulz, 1999) coping with disturbed

interpersonal behavior (WHO, 2005) and fatigue from continuous supervision of a family member have also been reported to add to caregiver burden. In addition caregivers have reported great anxiety due to fear that their relatives might attempt suicide (Polio, 2001).

The “Worried, Tired and Alone” survey, which set out to assess care giver burden in Western Australia revealed that many caregivers felt a deep sense of fear as well as powerlessness and helplessness which was a result of the unpredictable behaviours of the individual with mental illness (Mays et al., 1999). Behaviours which are commonly reported by family members in Australia are aggression, unpredictable mood swings, hostility, abusive language and the ability of the individual to appear normal one minute and on the edge the next (Baldassanol, 2004).

#### **2.4.5 Effects on mental illness on the physical and mental health of a relative**

Family members, who provide care for a family member with mental illness, are at increased risk of mental and physical health problems (Berg-Weger, 2000). In USA, caregivers of family members with a higher number of symptoms and level of cognitive impairment experience more depression. Rates of caregiver depression have been estimated to range between 38% and 60% (Berg-Weger, 2000). There is a relationship between caregiver burden and symptoms of infectious illnesses primarily upper respiratory tract infections. The severity of the patient's symptoms increases the number of infectious illnesses contracted by the caregiver (Dyke et al, 1999). In a study done in the USA, family members living with a person with bipolar disorder reported poorer physical health as well as limited activity and greater health service utilization than non care-givers (Baldassanol, 2004). While studies have shown that people with severe mental illness are more likely to become victims of violent crime (Teplin et al, 2005), violence is a stressor that affects family caregivers both emotionally and physically and among violent patients admitted into psychiatric institutions,

research shows that 50% of the time the violence will be directed at family members (Teplin et al., 2005).

## **2.5 Effects of specific psychiatric disorders on the family**

Some researchers have studied the effects of specific psychiatric conditions on the family and these disorders include schizophrenia, bipolar affective disorders, substance abuse, mental retardation and dementia. Only literature for the two conditions under study for this dissertation will be reviewed, that is: schizophrenia and bipolar affective disorder. The two conditions raise similar issues for family caregivers in terms of behavioural challenges, caregiver burden and social stigma and are the main conditions that are seen in our setting though there is no literature to justify this. These conditions were also chosen to give more coherent focus for this study.

### **2.5.1 Effects of schizophrenia on the family**

Schizophrenia is a seriously handicapping psychiatric disorder which leads to major disability and puts a considerable burden on families. It is characterized by delusions, hallucinations, disorganized behavior, negative symptoms (e.g., flat affect), and social and /occupational dysfunction (Oxford Dictionary, 2010). Schizophrenia affects mostly the age group 15 to 35 years with an incidence of 7 per 1000 in the adult population (WHO, 2012). About 90% of people with schizophrenia in low to middle income countries do not receive adequate treatment hence leaving the burden of care to families (WHO, 2012).

Individuals with schizophrenia experience lifetime emotional, financial and social challenges that have significant effects in their families. Family reactions to having a family member with schizophrenia manifest as care burden, fear and humiliation about illness signs and symptoms, insecurity about cause of the disease, lack of social support and stigma (Czuchta et al., 2001). The experience of caring for a family member with schizophrenia has often resulted in psychological distress and an aspiration to control behaviour problems (Shibre et

al, 2001). There is a desire by family members for social support as well as support from mental health professionals (Saunders & Bryne, 2002). Similarly Matern and Addington, (2001) in their study on experiences of care giving in Canada found that most family members reported significant distress, anxiety and feelings of hopelessness and helplessness. Stigma and stress were reported to increase the burden of care giving by Czuchra and McCay (2001) in Canada.

In across sectional study done in Nigeria, among 200 relatives of schizophrenic patients who were recruited from an outpatients' department, the results revealed that caregivers experienced financial burden (Osayi et al., `2010). An intervention in the area of employment and financial support for patients with schizophrenia was found to reduce the burden. These results supported the findings of a study by Ohaeil et al. (2001) in the same country which revealed that caregivers experienced a substantial financial burden as a result of a family member's mental illness. Awad and Voruganti (2008) in their systematic review on caregiver burden also found that the relatives of schizophrenic patients experienced objective burden which included quantifiable financial burden, as well as subjective burden, such as the impact on family relationships and socialization within the family.

An epidemiological study conducted by Shibre, Kebede, Alem, Negash, Deyassa, Fecadu, Jacobson and Kullgren (2003) in rural Ethiopia, which set out to assess the impact of schizophrenia on 301 patients and family members revealed that disorganized symptoms displayed by the patients affected the caregivers negatively in all domains despite a strong family network and recommended that family members should be educated on the condition. This was also supported by the findings from a cross sectional study conducted in Kenya among 107 patients and 175 relatives which revealed that the patients' disturbed behaviour such as verbal and physical aggression, refusal to go to the hospital as well as refusal to take medication affected the family members (Ndetei, Pizzo, Khasakhala et al, 2009).

In another study conducted in rural Ethiopia, 75% of family members of individuals with schizophrenia reported being stigmatized. Just over one third (37%) of the family members wished to hide a mentally ill member and 65% reported prayer to be a preferred coping method (Shibre et al, 2001).

### 2.5.2 Effects of bipolar affective disorder on the family

Bipolar affective disorder is also a severe mental illness that manifests in early life (Kessler et al., 2005). Its clinical manifestation includes episodes of mania and depression as well as changes in mood, energy and activity (American Psychiatry Association, 2013) and affects diverse areas of social performance (Dore & Romans, 2001). Caring for these patients can be very challenging to the family members who are involved in the formal care of the patient (Chang & Horrocks, 2006). The violent behavior that the patient exhibits is highly burdensome to the caregivers with 100% of the caregivers being affected by the verbal aggression (Lam et al, 2005). Another behavior that is highly burdensome is the reckless spending. Financial challenges are the greatest long term burden related in mania (Lam et al., 2005). The hyperactivity, decreased need for sleep, lack of insight, and unpredictability of the patient during manic episodes cause serious distress to caregivers (Lam et al, 2005). Disruption in role taking is magnified when the caregivers do not understand manic behaviours and may find these to be extremely frightening (Bauer et al., 2011). Decreased understanding has been associated with switches between mania and depression, caregivers' hopelessness and helplessness (Bauer et al., 2011). Caregiver burden related to bipolar disorder is associated with factors such as the number of episodes and coping styles of the caregivers (Goossens et al., 2008).

In a study conducted by Dore and Romans (2001) in Australia, caregivers reported significant difficulties in their relationships with the bipolar patient when he was unwell, and this impacted negatively on their own employment, social relationships and finances. Caregivers of persons with bipolar disorders with active symptoms as well as for those with



remitted symptoms were found to experience mental illness stigma (Gonzalez et al, 2007). Symptoms such as talkativeness and hyper sexuality during the symptomatic period are associated with stigma (Gonzalez et al, 2007).

A review by Steel et al., (2010) in the USA which sought to assess the psychiatric symptoms in caregivers of patients with bipolar affective disorder showed that 46% of these caregivers were depressed whilst 32.4% reported using mental health services themselves. Research on the experiences of living with a family member with bipolar disorder is very limited.

## **2.6 Coping strategies of family members with a mentally ill relative.**

Coping refers to cognitive and behavioural efforts to manage a troubled person-environmental relationship (Lazarus & Folkman, 1985). Pearlin and Schooler defined coping as “any response to external life strains that serves to prevent, avoid, or control emotional distress” (20, page 3). They stated that the act of coping is what one does to keep away from damage from life strains. These authors also emphasize that coping is related to both the state of one’s inner emotional life and life strains.

Coping strategies are summarized under two broad patterns of coping, namely problem focused and emotion focused coping mechanisms. Problem focused coping aims to tackle a problem directly by changing an aspect of a situation, whereas emotion focused coping refers to strategies regulating emotional responses to the problem (Folkman & Moskowitz, 2004).

### **2.6.1 Problem focused coping**

Problem focused strategies include behaviours such as problem solving, seeking information, or using positive methods of communication. These coping strategies are usually used by adult individuals in work situations (Lazarus & Folkman, 1984). Coping strategies can also be classified as being either positive or negative. Positive thinking and the utilization of appropriate social supports such as family, friends, and religious

organizations are some of the aspects of positive coping strategies (Perkins et al., 2004). The use of avoidance behaviors, negative thinking, and substance abuse are some examples of negative coping strategies (Nehra, 2005).

## 2.6.2 Emotion-focused coping strategies

Emotion focused coping strategies are reported to be less adaptive and attempt to modulate the caregiver's stress-related emotional response by use of avoidance or resignation (Magliano et al, 1999). Emotion-focused strategies involve dealing with the feelings that are brought up as a result of the stressor (Lazarus & Folkman, 1984). This can include managing bad feelings by counting one to ten, or reducing anxiety by meditation, cognitive distraction, seeking emotional support, emotional regulation and expression, selective attention, using relaxation techniques and reframing (Lazarus & Folkman, 1984). Demographic factors of patients and care-givers can determine the use of these coping strategies (Magliano et al, 1999).

Emotion focused strategies are more often used by younger caregivers and caregivers of younger patients whereas problem focused strategies are commonly used by older caregivers (Magliano et al, 1999). Emotion-focused coping strategies are used in health related situations (Lazarus & Folkman, 1984). Herman-Stahl et al. (1995) found that in adolescents, problem-focused coping strategies were more functional and they included, seeking information or advice, accepting social support and making efforts to solve the problem, whereas emotion-focused coping methods were dysfunctional and lead to withdrawal, and avoidance of the problem. This contradicts the findings of Mangliano et al (1999) above.

Avoidance is used by family members in situations where they underestimate their capability to deal with the problem such as in violent behavior of the patient (Nehra et al., 2005). Avoidance may include removing oneself from the uncomfortable situation or avoiding

discussing the situation or simply avoiding thinking about it (Nehra et al., 2005). Some families end up dissociating themselves from the patient totally.

Situations such as physical aggression of a patient can lead to the use of emotion-focused strategies in an effort to manage threatening behaviour (Scafuza & Kupiers, 1999). Caregivers of persons with severe mental illness often experience a considerable burden in coping with patients' symptoms (Scafuza & Kupiers, 1999). Factors which include social support, coping strategies and cognitive appraisal, have been thought to influence the impact of caring for a mentally ill relative (Scafuza & Kupiers, 1999).

Family members also use communication as a way of coping, for example sharing information about how they feel and think in relation to the illness of a family member (Lazarus & Folkman, 1984). This is considered to be an emotion focused way of coping. In mental illness however, families often find it difficult to communicate about the illness as a result of the associated stigma resulting in concealment of the illness (Stengler-Wenzke et al., 2004). The coping ability of the family is thus negatively affected by the stigma associated with mental illness (Stengler-Wenzke et al., 2004).

Some families of mentally ill patients use religious and spiritual strategies for coping with caring for a mentally ill family member. The use of spiritual means is considered to be a positive emotion focused coping strategy and has been seen to decrease the level of stress in one's life (National Alliance on Mental Illness, 2005). This can be through values and beliefs or through attending church and performing rituals. It may also include seeking advice from a church minister, attending church service and believing in God. Spirituality may also include praying alone privately or with others and this has been seen to reduce stress and improve well being among family members (Rammohan et al., 2002). Religious or spiritual coping strategies may not always be useful as the family member may retreat into prayer and withdraw from their mentally ill member, thus providing very little constructive care or support.

Another positive coping strategy used by families to cope with caring for a mentally ill relative is use of social support systems such as social networks, friends and extended family or formal networks such as health facilities (Lazarus & Folkman, 1984).

### 2.6.3 Coping Strategies in Schizophrenia

Coping patterns of caregivers of schizophrenia have received more attention than those of caregivers of bipolar patients. A cross sectional study conducted by Nasser-Hassan et al (2011) in Egypt revealed that caregivers of schizophrenic patient used positive appraisal and avoidance coping. Avoidance is a negative way of coping and may result in the patient not getting enough attention from the caregiver. This study was conducted among 100 caregivers of schizophrenic patients in an out patients' clinic. Another cross sectional study conducted by Shibre et al. (2001) in Ethiopia on the impact of schizophrenia among 178 family members of individuals with schizophrenia revealed that prayer was a frequently used way of coping by family members with sixty five percent of them reporting that prayer was the preferred way of coping. Most of the relatives (27%) attributed the illness to supernatural causes and used prayer for guidance (Shibre et al., 2001).

### 2.6.4 Coping Strategies in Bipolar Affective Disorder

Caregivers of patients with Bipolar Affective Disorder use both emotion-focused and problem-focused coping strategies. These coping strategies are dependent on the duration of the illness and the level of function of the patient. The longer the illness duration and lower the level of function the more caregivers use problem focused coping strategies (Chakrabarti & Gill, 2002). The coping style is also determined by appraisal of the illness by the caregiver and the burden they experience. For shorter duration of the illness and younger age of the patient, caregivers use strategies such as seeking spiritual assistance, collusion and coercion more frequently (Chakrabarti & Gill, 2002). Spiritual help is sought by caregivers who feel less in control of the condition and those who believe that the patient is in control of his condition more likely use collusion. Caregivers often feel that the first episode is the most

difficult to cope with as they will be ignorant of the signs and symptoms of the condition (et al, 1987). With subsequent episodes they then learn what to expect and are able to plan on how to intervene appropriately hence the use of more adaptive coping strategies.

A preliminary study done to examine coping in family caregivers of patients with bipolar affective disorder in USA, revealed that spouses were using strategies such as wishing the situation would go away which was an emotion focused way of coping (Fadden et al 1987). The illness is more disruptive if the patient is married and the levels of caregiver burden become higher hence the use of emotion focused coping strategies (Fadden et al 1987). This is because of the disinhibition displayed by the patient and the generosity they display during the episode. Caregivers belonging to a high social class cope by seeking more information about the illness, probably because information is accessible to them. Adoption of more adaptive coping styles can be achieved through reduction of burden on the caregivers and enhancing their awareness of the condition (Chakrabarti & Gill, 2002).

### 2.6.5 Comparison of coping strategies in caregivers of Schizophrenia and Bipolar Affective Disorder

In a cross-sectional study that was set up to compare coping styles in caregivers of bipolar patients with those of schizophrenic patients in USA, the results showed that caregivers used both problem-focused and emotion focused coping strategies. Demographic parameters, illness duration, levels of dysfunction, burden and social support, and appraisal by caregivers showed significant associations with coping styles of caregivers of bipolar affective disorder patients (Magliano et al., 1998). Problem-focused coping strategies were found to be more common in caregivers of bipolar patients whilst emotion-focused strategies were used mostly in caregivers of schizophrenic patients (Chakrabarti et al, 2002). Caregiver burden was higher in schizophrenia due to the symptoms exhibited by the patients during the acute phase. These differences appeared to be as a result of differences in caregiver-burden and appraisal between the two groups (Chakrabarti et al, 2002). It was concluded

that appraisal by the caregiver, and burden on caregivers play an important role in determining their way of coping. These factors contributed largely to the differences in coping observed between caregivers of patients of bipolar disorder and schizophrenia, in this study. A reduction in the burden of care giving among families and an improvement in their awareness of the illness could lead to implementation of more adaptive coping styles by them (Chakrabarti et al, 2002).

Another cross sectional study by Mehra et al (2005) in Canada set out to compare caregiver-coping in 50 patients each of bipolar disorder and schizophrenia and their caregivers and to explore the determinants of such coping. The study revealed that high levels of patient-dysfunction and caregiver burden were associated with coping styles in both groups. The other factors such as low awareness of illness and low perceived control over patient's behaviour were also associated with coping styles with no significant differences between the two groups on these areas (Mehra et al, 2005). It was concluded that coping and other elements of the care giving experience in bipolar disorder are no different from schizophrenia though the relationship between caregiver-coping and its determinants appeared to be a complex one (Mehra et al, 2005).

There has been a lack of qualitative studies on caregiver burden and coping, especially from non-Western populations. A longitudinal study on burden and coping in a group of caregivers of people suffering from schizophrenia and bipolar affective disorder was conducted by Ganguly et al. in (2010). Focus group discussions were carried out with the caregivers of both conditions over a period of a year. The results of this study revealed that caregivers reported burden in different areas of their lives which included effects on family functioning, social isolation, health and financial problems. They used numerous coping strategies including developing empathy in care giving and hoping for a better future. They also developed faith in God and participated in religious practices as well as helping others with a similar problem (Ganguly et al., 2010).

## **2.7 Needs for support by family members to cope with the mental illness of a relative**

Provision of information, using a problem-solving approach to help caregivers cope more effectively, and offering emotional and practical support have been found to reduce burden among caregivers in schizophrenia (Kupiers & Bebbington, 1995). Psycho-educational interventions have similarly proved useful in schizophrenia and these involve providing education, support as well as focused help with solving problems (Kupiers & Bebbington, 1985). These approaches can also be used for patients with bipolar disorders.

## **2.8 Summary of literature review**

Mental health service resources are inadequate in LMIC, and even in HIC, where resources are relatively more available, the shift towards community-based care has frequently increased expectations on families to provide care for people with mental illness (Stern, 1999; Chamber, 2001; Seloilwe, 2006).

Mental illness in different societies is viewed as a family problem (Lauber & Rossler, 2002; Yang, 2007; Yip, 2003) and most non-hospitalised individuals with mental illness live with their families (Schwart & Gideon, 2002; Yip, 2004; Zauszniewski et al., 2009). People with mental illnesses such as schizophrenia and bipolar affective disorder rely on their families for continued care and support throughout their lives (Fujino & Okamu, 2009; Moller et al., 2009; Zauszniewski et al., 2009). Families provide housing, financial support and rehabilitation to their mentally ill relatives (Marsh & Johnson, 1997; Solomon et al, 1996; Sun & Cheng, 1997).

Families worldwide are inadequately supported to provide care and support for their mentally ill relatives and struggle to look after them (Doornbos, 2002; Mangliano et al., 2005; Yip, 2005; Leong et al., 2010). Mental illness has physical, psychological, emotional, financial and social implications for family members. Numerous studies in Western countries have shown that family care giving causes stress, depression and financial difficulties (Wancata et

al., 2006; Awad & Voruganti, 2008). Similar studies have been limited in developing countries including Zimbabwe.

Stigma associated with mental illness in families has resulted in strained relationships within the families themselves as well as relationships with neighbours and the society at large (Struening et al., 2001) and this has been attributed to the misunderstanding of mental illness aetiology (Shibre et al., 2001). Stigma has been found to be linked with depressive symptoms among families of patients with mental illness (Phelan et al., 1998; Perlik et al., 2001).

Both emotion focused and problem focused coping strategies are used by caregivers of mentally ill patients and these are determined by demographic attributes of patients and caregivers (Mangliano et al., 1999). Problem focused coping strategies are usually used by younger caregivers whilst emotion focused strategies are prevalent among older caregivers (Mangliano et al., 1999; Herman-Stahl et al., 1995). Currently there is no documented evidence on which coping strategies are used by caregivers of the mentally ill in Zimbabwe.

Caregivers of patients with both bipolar affective disorder and schizophrenia have been found to require emotional support, psycho education and information about the illness for them to effectively provide care and support to their mentally ill relatives (Kupiers & Bebbington, 1995). Support groups and counseling have also been found to be helpful (Mittlelman et al., 2006).

There are very limited reliable and valid data on care giving in families in Zimbabwe with only one study conducted more than a decade ago by Wintersteen et al (1995). Most studies have been done in Western countries (Aschbrenner, 2009; Moller et al., 2009; Van Der Voort et al., 2007) and their results are unlikely to be generalizable in the Zimbabwean context due to the difference in the characteristics of the populations.

It was therefore important to assess the emotional, psychological, financial, social and physical impact of caring for a mentally ill family member among Zimbabwean family



members. It was also important to assess the stigma associated with caring for a mentally ill relative in order to document and compare the findings with those from other countries. In addition it was crucial to determine what sort of psychosocial support family members required to help them cope with the illness and reduce the likelihood of developing psychiatric and psychological disorders. Such data could assist in policy formulation, health care planning, strengthening and evaluation of health care and support of patients with mental health problems in Zimbabwe as well as their caregivers.

## **CHAPTER 3**

### **METHODS**

#### **3.0 Introduction**

This chapter discusses the study design, population, inclusion and exclusion criteria, sampling procedure, sample size, instruments, data gathering procedure, data management and analysis, and ethical considerations.

#### **3.1 Study Design**

The study design was descriptive and used both qualitative and quantitative techniques. Qualitative research helps to understand a given research problem or topic from the perspectives of the local population it involves (Weijer, Goldsand & Emanuel, 1999). Qualitative research is especially effective in obtaining culturally specific information about the values, opinions, behaviors, and social contexts of particular populations (Rappaport, 1995; Weijer et al., 1999). A qualitative approach was purposely selected for the present study in order to identify the experiences of family members, and to consider their points of view regarding their coping strategies and needs. This type of data is difficult to obtain quantitatively. This could lay the foundation for future quantitative observational and intervention studies.

In conjunction with the qualitative data, quantitative data were collected from consenting relatives in the form of their socio-demographic characteristics and the self-administered 14-item Shona symptom checklist (Patel et al, 1997). This was done to assess the extent of the psychological impact of care giving and this was completed after the in-depth interviews and focus group discussions.

## **3.2 Setting**

The study was conducted at Annexe Psychiatry Unit. This setting was chosen as it is one of the major referral Psychiatry Institutions in Harare catering for about 200 outpatients per week. The unit has an admission capacity of 36 beds for both male and female adults. This institution caters mostly for civil patients as well as a few forensic psychiatric patients who are assessed and referred to specialist institutions. Patients are referred to the Annexe from primary health care facilities and regional hospitals in Harare as well as surrounding rural areas. It caters for half of the population of Harare which currently stands at 1 896 134 (Central Statistics, 2002) with the other half in the catchment area attending Harare Psychiatry Unit.

## **3.3 Population**

Participants were drawn from family members who accompanied patients diagnosed as having schizophrenia and bipolar affective disorder to Annexe Psychiatry Unit either for review or admission.

## **3.4 Inclusion Criteria**

Family members who were involved in the care of patients diagnosed as having schizophrenia or bipolar affective disorder and attended Psychiatry Unit for review or admission and who were above 18 years were invited to participate in the study.

The family members included siblings, parents, spouses, aunts and children. Only consenting relatives of civilian patients were recruited into the study.

### **3.5 Exclusion Criteria**

Family members who were 17 years and below, and those who were not directly involved in the care of the patient were excluded from the study.

Family members of patients with psychiatry conditions other than schizophrenia or bipolar affective disorder were also excluded from the study.

Family members were also excluded if the patient was having a first episode of the illness, as they may not have had sufficient experience of caring for their mentally ill relative to answer the main questions of the study.

### **3.6 Sampling Procedures**

Participants were drawn from relatives who accompanied patients diagnosed with schizophrenia or bipolar affective disorder to Annexe Psychiatry Unit either for review or admission from July to September 2012. A purposive sampling technique was used to select adult relatives who met the above inclusion criteria. A principle of sampling for maximum variation was followed, to include all family member types who included siblings, parents, spouses, aunts and children and a wide range of socioeconomic status.

### **3.7 Sampling**

In purposive sampling the size of the sample is determined by the information required for consideration, and sampling is conducted until theme saturation is achieved (Pope & Mays, 2000). Qualitative samples are often small for example 20-30 participants. To recruit participants who met the above criteria in this study, psychiatric nurses working in the unit were informed about the purpose of the study, and required characteristics of participants. The psychiatric nurses consecutively identified and recruited family members who were waiting in the queue. Both family members and the patients were then referred to the researcher. The patients' files and outpatients' cards were checked by the researcher to

confirm the diagnosis of either schizophrenia or bipolar affective disorder which had been made by the attending doctors. The researcher did not attempt to re-diagnose the patients. The study was then explained to the relatives and informed consent was sought together with verbal consent from the patients. This was done for both in-depth individual interviews and focus group discussions. For focus group discussions the psychiatric nurses further explained that the participants were going to have a group discussion. Selection was similar for both in-depth interviews and focus group discussions. However in the case of focus group discussions, participants were selected who had diverse relationships with the patients, in order to facilitate a discussion of diverse experiences.

Sampling was discontinued after completing 9 in-depth individual interviews after which information saturation was reached as there was no new information forthcoming from newly sampled participants. Three focus group discussions with groups of spouses, parents, siblings and aunts each comprising of 9, 6 and 7 participants respectively were conducted to triangulate the data. Group participants were family members of schizophrenic and bipolar affective disorder patients who had not been involved in the in-depth interviews and these were conducted throughout the study period, until no new information came up. A total of 31 family members participated in the study. In-depth interviews and focus group discussions were conducted using standardized study guides attached as Appendix D and F respectively.

### **3.8 In-depth interviews**

In-depth interviews are optimal for collecting data on individuals' personal histories, perspectives, and experiences, particularly when sensitive topics are being explored (Boyce, 2006). Intensive individual interviews allow the researcher to explore the person's perspective on a particular area. In-depth interviews are also useful in eliciting detailed information about a person's thoughts and behavior and in exploration of new information (Boyce & Neale, 2006). In this study in-depth interviews were conducted in order to elicit

caregivers' experiences of caring for a mentally ill relative, their ways of coping with the illness and the needs that they had.

The researcher described the purpose of the study to family members prior to the interviews as well as the expected duration of the interview, which in this case was between 30 and 45 minutes. The participants used the most common local language during the interview which was Shona. The researcher posed questions in a neutral manner, listened attentively to the participant's responses and asked follow up questions and probes based on the responses. The participants were not encouraged to provide particular answers, neither was approval or disapproval expressed. Data were audio recorded and transcribed verbatim.

### **3.9 Focus Group Discussions**

A focus group is a formal discussion that is undertaken among a group of selected participants. It is normally conducted for the purpose of discussing a particular topic and is focused because it involves some collective activity (Wilkinson, 2004). Three focus group discussions with 9, 6 and 7 participants respectively were conducted during the study period. Focus groups also allow for interactive discussions between participants, which may elicit new and sometimes unexpected finding quickly (Kitzinger, 2005). These were done to triangulate the data obtained from in-depth individual interviews, and to elicit new information from the interactions between group participants.

After identification and selection of the participants from among the caregivers who had accompanied patients to Annexe Outpatients departments, the researcher described the purpose of the study. This was done prior to the discussions. The expected duration of the discussion was also explained to the participants. Ground rules were made prior to the discussion which included switching off cell phones, giving each other the opportunity to talk and not to respond at the same time, ensuring that information discussed is kept in confidence, avoiding arguments and respecting each others' opinions. The participants used the most common local language during the focus group discussions, which was Shona. The

researcher posed questions in a neutral manner listened attentively to the participant's responses and discussions and asked follow up questions and probes, based on the responses. The participants were not encouraged to provide particular answers, neither was approval or disapproval expressed. Data were audio recorded and transcribed soon after the discussion. The researcher also took notes which were used to either probe more deeply or seek clarification from the participants.

## **3.10 Instruments**

### **3.10.1 An in-depth interview guide**

This interview guide was developed and used during the individual in-depth interviews. Relatives were asked to describe the household in which they live, explain how the mentally ill relative is cared for in the household and identify the problems that they faced. The questions included: the burden of mental illness on families; their experiences of having a mentally ill relative; how the illness has affected the family in terms of finances, socializing, and their general physical health; any stigma experienced as a result of having a mentally ill relative; how they had been coping with the illness; and what kind of support they needed to help them cope with their ill relatives. Themes that emerged from the literature review were explored, for example problem-focused versus emotion-focused coping strategies. Interviews of relatives took place over a period of two months. The in-depth interview guide is attached as Appendix C.

### **3.10.2 A focus group discussion guide**

This discussion guide was used during the focus group discussions, which on average lasted an hour. Three focus group discussions were held in order to triangulate the in-depth interview findings among family caregivers of schizophrenia and bipolar affective disorder respectively who had not been involved in in-depth interviews.

As for the IDIs the questions asked about the impact of mental illness on families; their experiences of having a mentally ill relative; how the illness has affected the family in terms of finances, socializing, and their general physical health; any stigma experienced as a result of having a mentally ill relative; how they had been coping with the illness; and what kind of support they needed to help them cope with their ill relatives. The focus group discussion guide is attached as appendix D.

### **3.10.3 The self-administered 14-item Shona Symptom Questionnaire (SSQ)**

The SSQ was used to assess whether consenting family members had symptoms of anxiety and depression (Patel et al., 1997). It was conducted after both the in-depth interviews and focus group discussions. The SSQ is attached as Appendix B. Participants were asked to indicate whether they have noted any of the 14 symptoms listed in the scale in the previous week. The purpose of administering the SSQ was to determine the extent of psychological morbidity (namely anxiety and depression) among caregivers of patients with bipolar affective disorder and schizophrenia.

## **3.11 Data gathering procedure**

A private room was identified at the Annexe Outpatients Department for the in-depth open ended exploratory interviews and focus groups and for the self administered 14 item Shona Symptom Questionnaire to ensure privacy and confidentiality.

## **3.12 Data management and analysis**

Interviews were audio recorded and transcribed verbatim in Shona. Names or other personal identifiers were removed from transcripts before they were translated from Shona into English by a bilingual speaker. The bilingual speaker was identified from the linguistics department which is located at the University of Zimbabwe and later back translated and



cross checked by another independent professional bilingual speaker from the same department. For quality control purposes, the researcher randomly selected one in every four interviews to monitor the quality of translations through back translations which were performed by another professional translator. English transcripts were transcribed and coded.

Transcripts were then entered into NVivo 8 (QSR International, Australia), a qualitative data storage and retrieval program to facilitate analysis. Analysis used the thematic approach (familiarization, identifying a thematic framework, indexing, charting, mapping and interpretation) (Smith & Firth, 2011). All transcribed and translated data were read and re-read for emergent themes which were then coded and classified under three domains, impact of mental illness, coping strategies of caregivers and their reported needs. This was done with the aid of a qualitative data analysis specialist. After coding, 15 agreed sub themes emerged. Care was taken to ensure that the codes accurately captured the respondents' meaning. A constant comparative method was used to identify similarities and differences between the responses. Iterative analysis was done in between the interviews until theoretical saturation of primary questions in the interview guide was reached. Quantitative data obtained from the SSQ 14 was captured using Epi Info 7 and analysed using Statistical Package for Social Sciences (SPSS) version 16. Pearson correlation test for association was conducted at a significance level of  $\alpha = 0.05$ .

### **3.13 Ethical considerations**

#### **3.13.1 Consent**

The relatives were assured that their participation was voluntary and that they were not under any obligation to participate in the study. They were informed that if they declined to take part, the care and treatment given to their relatives was not going to be affected in any way. The researcher obtained informed consent from the relatives, which is a mechanism for ensuring that people understand what it means to participate in a particular research study

so they can decide in a conscious, informed way whether they want to participate. The Informed consent form is provided in Appendix A. The purpose of the study was also explained to the patients and assent obtained to prevent possible resentment, ill feeling and paranoia. No names were written on any form but code numbers were allocated in order to maintain confidentiality. Questionnaires, consent forms as well as the audio recorder were kept in a lockable cupboard for confidentiality purposes, for the entire study period. Only the researcher had access to the keys. The information will be destroyed one year after the results are disseminated.

Ethical approval was obtained from the Joint Research Ethics Committee at the University Of Zimbabwe College Of Health Sciences (reference number: JREC/156/12) as well as the Medical Research Council of Zimbabwe (reference number: MRCZ/B/385). Approval was obtained from the chief executive officer of group of hospitals as well as the matron in charge of Annexe Psychiatry Unit. Permission was also obtained from the University of Cape Town Faculty Of Health Sciences Human Research Ethics Committee (REC Ref number 262/ 2012).

# **CHAPTER 4**

## **RESULTS**

### **4.0 INTRODUCTION**

This chapter presents the socio- demographic data, an overview and description of the themes that emerged from the qualitative data, as well as the SSQ results. The data is presented in tables and figures. The aim of this study was to explore the perceived impact of mental illness, reported coping strategies and reported needs of family members of mentally ill patients attending the Annexe Psychiatry Unit in Harare, Zimbabwe.

A total of 31 family members participated in the study. The mean age of the respondents was 44 years. The minimum and maximum ages of the respondents were 22 and 69 years respectively. Thirteen (42%) were caregivers of patients with bipolar disorder whilst 18 (58%) were caregivers of patients with schizophrenia. The majority of respondents 21 (68%) were female whilst 10 (32%) were male. Twenty (65%) were married and all participants had some form of education. Eighteen (68%) lived in high density suburbs whilst 13 (42%) lived in low density suburbs. Most of the participants 30 (97%) belonged to some religion. Eight (26%) were employed whilst 23 (74%) were unemployed. The Sociodemographic characteristics of participants are shown in Table 2 below.

Table 2: Socio-demographic Characteristics of respondents

Variable	Frequency (n)	%
<b>Gender</b>		
Male	10	32,3%
Female	21	67.7%
<b>Marital Status</b>		
Single	2	6.5%
Married	20	64.5%
Divorced	5	16.1%
Widowed	3	9.7%
<b>Educational Status*</b>		
Primary level	7	22.6%
Junior certificate	4	12.9%
Ordinary level	9	29.0%
Advanced Level	7	22.6%
Degree Level	4	12.9%
<b>Place of Residence*</b>		
Low Density	13	41.9%
High Density	18	58.1%
<b>Religion</b>		
Catholic	8	25.8%
Pentecostal	18	58.1%
Traditional	1	3.2%
Apostolic	2	6.5%
Seventh day Adventist	1	3.2%
None	1	3.2%
<b>Employment Status</b>		
Employed	8	26%
Unemployed	23	74%

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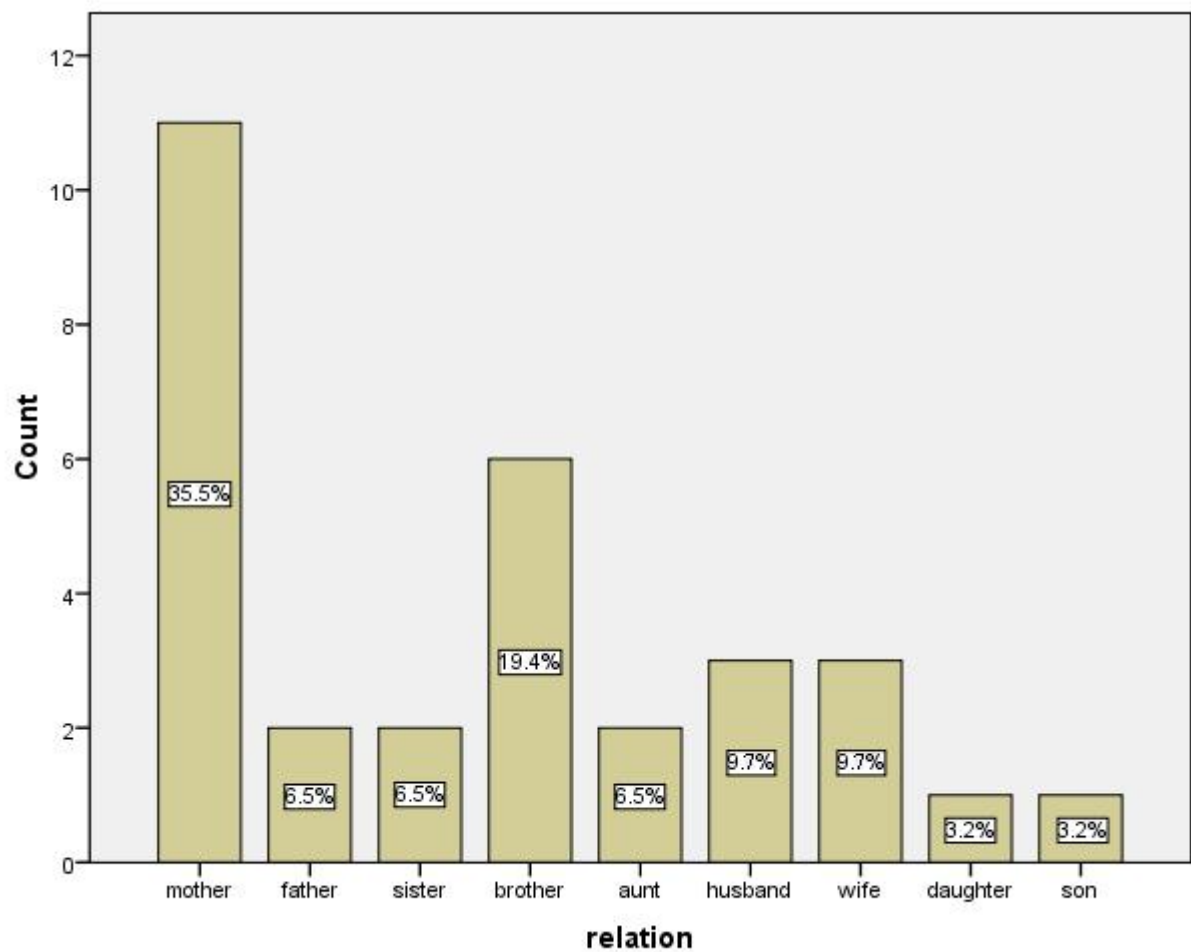
\* In Zimbabwe, high density suburbs are densely populated, with smaller property sizes and lower real estate value compared to low density areas (Nkomo, 2003).

\*The educational system in Zimbabwe consists of 7 years of primary education, 4 years of secondary education (ordinary level) and 2 years of advanced level (Ministry of Education and Culture, 2013).

### **Relationship of Family member to the person with mental illness**

Figure 1 below illustrates the relationship of the caregiver who was interviewed to the patient: Eleven (35.5%) were mothers, 2 (6.5%) were fathers, 2 (6.5%) were sisters, 6 (19.4%) were brothers, 2 (6.5%) were aunts, 3 (9.7%) were husbands, 3 (9.7%) were wives, 1 (3.2%) was a daughter and 1 (3.2%) was a son.

**Figure 1: Relationship of respondent**



## 4.1 Qualitative study Results

In this chapter the results of the qualitative data are structured according to the objectives of the research namely: impact on the family, coping strategies and needs for support. These overarching domains are further broken down into themes and sub-themes according to what emerged from the data as set out in Table 3 below.

Table 3: Domains, Key Themes and subthemes

Domains, key themes and sub themes on the impact of a relative's mental illness on the family members, their reported coping strategies and needs.	
Domain	Key Themes and sub themes
Perceived impact of a relative's mental illness on the family members	<p><b>Psychological and emotional impact:</b> Crying, Kufungisisa (Thinking too much) Fear of the person</p> <p><b>Physical impact which included:</b> Being beaten, physically hurt</p> <p>Body response due to the impact (ears closing), back painful, high blood pressure (BP)</p> <p><b>Financial/material impact:</b> Spending money on person's treatment, Damage to property (furniture, car), Loss of time to generate income/grow own food.</p> <p><b>Social impact:</b> Stigma (resulting in efforts to conceal), Blame (husband/family member blaming of women), Rejection (by family and society more widely), Caregivers become jealous (think others laugh at them)</p>
Coping Strategies used by family members with a mentally ill relative	<p><b>Seeking spiritual assistance</b> in a manner which is linked to understanding of aetiology (witchcraft or evil spirits): from Traditional Healers prophets, Church/pastor/priest.</p> <p><b>Confrontation</b> (due to suspicion that patient is acting out),</p> <p><b>Resignation</b> (or ignoring the problem)</p> <p><b>Alcohol use</b></p>
Reported needs by family members with a mentally ill relative	<p><b>Financial/material:</b> Money for subsistence, Money for food, Food, Money for medication/patient upkeep, Money to start income-generating activities/establish self-reliance, Support groups, Training (for taking care of patients), Information (including written materials), Health care worker support, Divine intervention, Comfort and hope</p>



## OVERVIEW OF THEMES

### 4.2 Perceived Impact of Mental Illness

Six broad themes characterized the impact of mental illness on the family members. These included physical harm or illness, psychological and emotional impact, financial burden, material burden, social factors as well as stigma as shown in table 3 above.

#### 4.2.1 Physical harm or illness

Participants reported that caring for someone with mental illness can be a challenging and very difficult experience. Due to the lack of adequate mental health services in Zimbabwe, participants reported having to bear the burden of looking after their mentally ill relatives and ensuring that they get the proper treatment and care. In the process some patients were described by participants as being physically and verbally aggressive to their caregivers. Discussions with caregivers of mentally ill family members suggested that they experienced physical harm in the form of assault especially when the patient had relapsed. As one participant stated:

“Yes it has affected us especially my husband he was assaulted and got injured. For me I was once assaulted by him but there is nothing to show but as for my husband he was hurt”. (R4)

Yet another participant mentioned that:

“There was a time when he stopped medication and got so ill to the extent that he would lift up hoes and axes wanting to murder someone.” (FGDR 5)

Less direct physical harm can occur to caregivers as a result of the stress they live under. Caregivers described physical symptoms that they attributed to living with the daily burden of caring for the patient. One participant reported,

” But now I realise that since I have been back here I have lost a lot of weight, I can’t even wear my trousers, they are huge, they are big, I just have lost weight because of the illness and at times I can’t even eat it’s very difficult”. (R2)

This participant was 69 years old and female. She was the mother of the patient and the response was given during the individual in-depth interview. The participants reported that it was very difficult to stay with their mentally ill family member, especially when they experience acute symptoms. Caregivers said that most of the time they do not have the resources to cope with these demands and become stressed to an extent that they develop psychosomatic symptoms. Some relatives attributed these symptoms to the patients’ condition.

“My ears ended up closing and today my back is painful I have problems standing up in the mornings. My legs and my body it’s like they have been dismantled and I were alone”. (FGD2)

Another participant reported that her/his daughter’s mental illness had caused high blood pressure.

“I now have high blood pressure because of the illness of my daughter.” (R6)

Another participant also explained how he ended up with high blood pressure.

“I was really affected a lot because when we were staying with him he was always threatening that he would murder someone several times the whole night. This affected me and I started having high blood pressure and the blood pressure was always high and took time to come down despite the medication that I was taking until I went to the hospital for treatment and I was praying and doing everything and the blood pressure was going up and I ended up nose bleeding because of the high blood pressure”. (FGD2)

### 4.2.2 Psychological/emotional impact

Other than the physical impact, caregivers were also affected emotionally and psychologically. However, some respondents reported little support from health workers for their distress. As one caregiver said:

“When I was at the Annexe when I was waiting from morning until around 3pm when I got in I started crying and there is not even one nurse who realised that I was breaking down. They could just see that I was sitting and crying and they kept on saying if you keep on crying we will give you an injection instead of the patient. So I was really pained to an extent that my I could not even manage to tie my dook [barque]. You see my eyes like they are not straight this happened because of the pain and the crying that I went through and before I never used to have painful eyes but because of my son’s illness I am now wearing spectacles....”[Starts crying] (R2)

The other psychological impact that was evident among the participants was the Shona term “kufungisisa”. The term was used frequently by participants to describe the emotional or psychological impact of living with a mentally ill relative. This Shona term is translated as “thinking too much” and is frequently associated with depression. For example,

“Now I am always thinking too much and I now have high blood pressure because of the illness of my daughter. This is really eating me inside, you can’t be happy as a family when someone is not feeling well within the family”. (FGDR1)

“I can’t stop thinking like you were given a child by God and you see him grow nicely and all of a sudden the child changes especially when I see his peers I see that my child would be doing this and that but now he can’t its really painful.....” [Starts crying] (R3)

Participants reported that the process of caring for someone with severe mental illness brings about the risks of mental ill health to the caregiver that can be in the form of

depression or emotional stress. Participants said that the caring process can be very tiring especially if the patient has severe mental illness and long term care can be a source of stress. The majority of participants expressed fear of the patients as they have a potential of violence. For this reason some participants had to ensure that the demands of the patient are met.

"This illness is very stressful to me and those who are in a similar situation of having to cope and look after family members suffering from mental illness". (FGDR3)

"I have to meet his demands in fear of getting beaten up". (FGDR2)

#### 4.2.3 Financial/ Material Impact

Financial burden was expressed by many family members and this took several forms. For some, financial burden was experienced as a result of the caregiver having to leave their jobs in order to take on a care giving role. For others, the responsibility of caring for the mentally ill family members lay within the family and they had to ensure that they finance the patients' up keep. This led to long-term reliance on small pensions, through older family members taking early retirement as well as exclusion from the workforce and loss of advantages that employment brings. In one case, absenteeism from work due to the patient's mental health problems resulted in the caregiver being dismissed from work and losing their main source of income. Caregivers stated that although treatment is free at Government Psychiatry hospitals, the family has to take care of the transportation costs for the patient to attend monthly reviews. Some caregivers said that they had to buy medication for the patient if it was not available at the hospital.

"Me I used to do things on my own and never used to stay at home I would go out to my aunt who has what do you call it this tailoring business. We used to do what could help us but I left everything and I even told the doctors. I left everything to come here

and stand by his side instead of wandering up and down around the streets like what I see others do in the streets". (R2)

"In terms of finances we have challenges money is a problem but you struggle as a parent but it's hard the father says we should spend even if we don't have if it is going to benefit the child there is no problem". (R3)

The majority of caregivers reported having financial difficulties and some had specific needs, reporting how they wished they could be given food hand-outs. They complained that the patients were eating too much, possibly as a side effect of the medication which they had no control over. Some participants said that they were no longer able to grow their own food, which was catastrophic as many rural Zimbabwean families rely on subsistence agriculture for their survival. They said that they had to stay in town and monitor the patients and accompany them for review.

"Ah it has affected us so much because if you look at this year I left home after ploughing the fields and I never went back to harvest the crops even up to now". (R4)

They said that the patients pose a lot of demands on the caregivers, such as demanding money to buy cigarettes and other things. One mother said that her son was demanding money to buy his own choice of food and did not want to eat what was available at home at that time.

"I have to meet his demands for money in fear of being beaten up". (R4)

#### 4.2.4 Social or Other

The social impact was linked to beliefs about the causes of mental illness such as witchcraft. The patient's illness and differing interpretations of its cause and meaning gave rise to tension within some families. Family members often argued about which route to take to get

help for the patient. Some believed the illness was biological whilst others thought it was as a result of evil spirits and punishment from the gods for wrong doings.

The caregivers said that the patients' symptoms also caused a lot of tension within the family. A mother described how her daughter would wake up in the middle of the night and try to open the door saying that there were people calling her outside. Everyone in the home would be up the whole night because of the noise the patient was making. This was described as stressful to the whole family and resulted in the patient being criticised or labeled by family members and this may lead to worsening of the symptoms. The caregivers said that there is a lot of anger among the family members which came about especially when the condition had not been explained to them.

Participants reported being rejected by relatives because of the patient's illness. It also emerged that the extended family were often unsupportive when there was illness within the family and this was mainly related to the beliefs about the cause of the illness as well as the patient's symptoms. Visits to the affected family declined along with social support. The affected relatives relied on friends and the church for support. A mother described how she was rejected by her own mother as well as her own siblings due to the illness of her son.

"Yes and that destroyed the family to an extent that even now I don't have anyone that I can confide in. My mother denied me as well as my sister and up to now I don't talk to them because of this illness. All my relatives told each other that if they see my son they should shut the doors so this is my situation". (FGDR3)

Some of the caregivers reported being unable to attend social gatherings because they had no one to leave the patient with and could not leave the patient un- attended. One mother described how uncomfortable she was to take her son to church because she did not want people to know or to realise that her son was mentally ill.

"I go with him to church when he wants but if he does not want I leave him like that I don't want people to realise that there is a problem because he has always been like

that. When we get to church I tell him to sit at the back and when the church is over we quickly go out without anyone realising he is not well and we go home". (R1)

Caregivers wished there could be some kind of day care for these patients so that they could get some respite from care giving. One mother expressed how she wished she could have somewhere to leave her son so that she could go to church.

#### 4.2.5 Stigma

Stigma was another theme that emerged, associated with having a mentally ill relative. Families reported that they do not only bear the burden of caring for the patient and all financial expenses but are also ostracised and isolated. The care givers expressed that there was still a lot of stigma associated with mental illness and they attributed this to lack of knowledge on the part of their relatives as well as the community at large. Some participants felt that mental illness was more stigmatised than HIV/AIDS and wondered why that was the case since they thought mental illness had always been there before the AIDS pandemic.

"Yes because of the stigma that is in the community because people in the community don't understand what mental illness is all about. They think that you are a witch, or that you killed your husband or that you have avenging spirits and the area where we are staying even the church people don't understand that this boy is mentally ill and they don't even come to fellowship with him. They isolate him and he feels the stigma and he goes back into withdrawal and there is no community behavioural therapy. So the whole problem is mine". (FGDR4)

The caregivers said that mentally ill patients are still being shunned by the society and still being given labels of being 'mad' and not ill. This is also because of the beliefs about the causes of mental illness that it is punishment for wrong doings by the ancestors. Participants felt that mental illness exposes them for their wrong doings.

“Relatives and outsiders don’t accept that these people are mentally ill. They look down upon them and like in my case my child is so forgetful so others don’t want to mix with her like at times she can be asked that “do you know this” and she will say “I don’t know” then they will say “You see she is mad”. When people look at her they will see that she is a normal person but get surprised why she is behaving like that. Society does not accept them”. (FGDR6)

The caregivers said that people in their communities believe that if you have mental illness you are a sinner. The caregivers reported seeking spiritual assistance first because of their beliefs about the causes of mental illness and societal reluctance to accept mental illness.

The caregivers also said that the stigma associated with mental illness resulted in efforts to conceal the problem on the part of the care givers. They also got embarrassed by the illness and ended up trying to hide the mentally ill relative. A mother described how she had always pretended that everything was fine by not telling her relatives that her son was mentally unwell. She went on to say that she did not want even her neighbours to know for fear of being embarrassed. The caregivers said that in the early stages the family did not seek assistance because they tried to put up with the symptoms and it is only when the symptoms worsened and were unmanageable that they sought medical attention. They said that in our society, mental illness is associated with things like eating from the bins, roaming around the streets with very dirty clothes and talking to one’s self among other things, hence the fear of stigma on caregivers.

“My neighbours do not know that my child has mental illness. Even relatives we tell them that we are okay. Very few close friends, very few know that the child has a problem...” (R6)

Caregivers especially women reported being blamed for the illness of the family member. Women reported being accused of bringing the illness into the home and one of the women got to the extent of being divorced by her husband due to their son’s illness. Some women



were accused of being witches and some were blamed for the patient's symptoms saying the patient was not ill but pretending.

"The other problem that we face is blame like in my case. Me the person who is not feeling well is my child, yes the person who is blamed is the wife that in the husband's family there is no illness like that so most of the time they suspect that it is you who came with what: with this illness to the family. So from the time it started my husband said, "This is from your family because in our family we don't have such things and in our family we have never encountered such things, it's you who brought it to the family", this is why I have been saying this mother who spoke last was talking about my problems. At times I cry when I think about this". (FGDR2)

Some of the caregivers expressed being rejected by the Church, which was the main source of support that they had relied on. One participant said that mental illness affects religiosity and the individual ends up with no willpower to do certain things that they used to do like attending social gatherings for example, and going to church.

"Even the church rejected me because they were not seeing me properly because all the time I would come with this violent person. All my relatives rejected me and when I came to visit him in hospital the people would just look at me and for that matter the patient himself could not understand the gravity of his illness. The problem that I see is that there is a lot of stigma". (FGDR4)

Women participants said that in our society, men always want to get the praise for all the good things that happen to their children but when things go wrong it is the women who are blamed. Some of the family members said they became jealous and suspicious of other people thinking that when they expressed happiness they were laughing at their situation:

"It is difficult to understand I don't know why, it is difficult to explain. Some will be eating and celebrating ahhh it is very difficult to understand". (R4)

“As for me I would be searching for my child and they will be laughing, yes laughing and celebrating”. (R5)

## **4.3 Coping Strategies**

Participants identified a number of coping strategies that they had been using to try and cope with the illness of their relative. Both emotion focused and problem focused coping strategies were used in bipolar affective disorders and schizophrenia. The themes that emerged from coping strategies were linked to the participants’ understanding of the causes of mental illness. For example seeking spiritual assistance from traditional healers and prophets was associated with belief in witchcraft and evil spirits.

### **4.3.1 Seeking spiritual assistance**

Those family members who were employed took time off from work or absented themselves in order to accompany the patients for review. One mother explained how her husband had made a vow that they would spend whatever amount of money they had in order to ensure that their son gets better. The most common coping strategy used was seeking spiritual assistance from both traditional healers and prophets. This was frequently informed by the belief that the problem was linked to witchcraft:

“It’s true we looked for help from prophets and ngangas [traditional healers] but it’s her father who did that when he was still alive”. (R2)

“We started by going to some Nganga and he would get better for a short time and it was not working and I would go there on my own my husband did not want to go with me. When I talk about my child or just his name he would start getting very angry”. (R4)

“As for my child he started being ill when he was grown up and they said it was because of stress so I once went with him to my church called ZAOGA and he was

prayed for and was alright but then he went to the village and when he came back he was worse and now he is refusing to go to church he will dodge me". (FDGR2)

Despite the fact that most people believed in seeking assistance from the traditional healers, there are some caregivers who said that they resorted only to the church as their source of assistance. One participant said that, the belief that a person can pray to God and get help acts as a source of comfort for her and that it also gives her an opportunity to offload the responsibility for dealing with her own problems. She went on to say that prayer is also seen as less inhibiting than talking to friends, relatives and health professionals.

"For me I have never gone to a traditional healer, I go to the Roman catholic church and I trust in God who created my child and I have asked the priest to pray for him". (FDGR1)

#### 4.3.2 Confrontation

Some family members reported using confrontation as a coping strategy:

"I shouted at him twice to say shut up and he says do you want to hit me and I was really fed up with his behaviour and useless talk". (R2).

Another participant explained how she would shout at the patient, not because she wanted to, but out of frustration from her husband who was failing to accept the illness and this was now having negative effects on her marriage.

#### 4.3.3 Resignation

Other family members reported using resignation (giving up on the patient) as a coping strategy because of the patient's continuous negative behaviour and especially during the psychotic period, for example:

“Yes, I avoid the patient, I just go outside because he doesn’t show respect to anyone and I have come to a stage where I say I don’t want to live with my son, I can’t live with him anymore, there is no peace, we can’t speak to each other. I am sorry I can’t live with him anymore, I can’t, and I can’t take it anymore”. (R2)

#### 4.3.4 Alcohol abuse

Some participants also reported alcohol use as a way of coping for example:

“Yes me I really broke down and because there were three people who were sick at that time and you would wonder who would be the next so I ended up drinking alcohol because the situation was very stressful”. (FGDR3)

Another participant explained how her husband ended up taking alcohol as a means of coping with the illness:

” As for me no, but the father did take alcohol”. (R6)

Participants said that roles had to be adjusted as well in order to cope with the illness. Some women said that at times they had to take the role of the father as breadwinner when the father was the one who was mentally ill.

### 4.4 Caregiver Needs

The themes that emerged in this domain were financial and material needs with subthemes that included money for subsistence, medication, patient upkeep, income generating activities and self reliance. The other themes that emerged included support groups, training (for taking care of patients, Information (including written materials), health care worker support, divine intervention and the need for comfort and hope.

#### 4.4.1 Financial/material needs

Family members reported having financial difficulties in caring for their ill relatives and wished they could have financial assistance either from the Government or well wishers. Another participant wished to be assisted with food to give to the patient.

"Me according to my thinking I think if I can be assisted with food". (R3)

"They should assist us with money so that we can do projects whilst we are at home there. A child like this you can't give him to anyone to look after him for you. So it's better for all those who have these people at home the government should give them support so that they can manage to look after these children". (FGD R4)

Some family members felt that the Social Welfare Department should intervene and assist the patients with some money. Participants stated that the Social Welfare Department used to give a small amount of money for assistance for the poor families as well as free treatment vouchers to the mentally ill which is not the case now due to the economic situation in the country. Caregivers felt there was need to revive this in order to assist in the care of the patients. They also felt that creation of rehabilitation institutions could help train patients with self help skills so that they can be self reliant and this would ease their financial burden.

"Patients should be assisted by the social welfare especially those who are chronic and they cannot look after themselves even giving them \$100 a month or creation of rehabilitation institutions for them where they can be taken on the strength of the money that they have." (FGD R7)

#### 4.4.2 Support group

Family members strongly felt that support groups for people with mental illness and caregivers would help them cope with the illness. They went on to explain how support

groups had been successful in HIV/AIDS victims and felt that if they do the same for the mentally ill it would help.

"If they do like the one for AIDS it will be fine. Those people with AIDS support each other so we can also support each other I think but we need to be given money by the Government or other rich people". (R6)

"support groups are also good where they can have a meeting like once in a month and they can discuss in order to discuss on their welfare on their own and also the relatives can discuss on how they can be helped". (R1)

#### 4.4.3 Training for the caregivers

Many family members expressed the need for them to be properly trained to deal with psychological problems. Participants complained that they did not know what their relatives were suffering from because it has never been explained to them. They said that they just knew that their relatives had a psychiatric problem but were not aware of the specific diagnosis of the patient. Most of the participants said that they get so overwhelmed by the condition to an extent that they end up ignoring the patient or ill treating them for example:

"I think the challenge that most people have is that we don't have experience or knowledge in caring for people with psychological problems. It is difficult when we don't have any training". (FGD R7)

Another participant said:

"I think that this illness is not being taught well to the people here in Zimbabwe unlike in other countries. When I look at mental illness I think it's the most difficult illness than all other illnesses. This illness affects those who look after the patient more than the patients themselves because the one who will be ill won't know anything but it's a sword to the one who will be looking after them. You see all these people who

are here, its BPs [high blood pressure] only, only that they have and stresses only, only. When we come with these patients the one who they are concerned about is the patient". (FGD R2)

#### 4.4.4 Written materials

When asked if they would benefit from written materials, each family member expressed the need to have these so that they would read and have knowledge of the signs and symptoms of the condition:

"Written information is also helpful there is someone who once gave me a book about this illness and it helped me a lot we will know that if it goes this way we do it this way". (R2)

Another family member said:

"I then started looking for SADAG [South African Depression and Anxiety Group] books to read about the condition and I also got a disk that was entitled living with schizophrenia, so we ended up understanding the condition and even my son ended up understanding so information is very important". (FGD R4)

#### 4.4.5 Support from health care workers

The need for support by the Health care workers also emerged during the interviews. The family members expressed the need for doctors to have more time with them so that they can explain the condition and find out what challenges they are facing in caring for their ill relative. Most of the family members felt left out in the care of the patients. Family members felt it was important to have more contact with the Psychiatrist for them to better understand the condition and help them to cope better.

"I think the time that we get with doctors is very limited in such a way that you won't understand what is going on. If you get into a session for 5 minutes, you get a

prescription and you go it makes it difficult to ask questions and make you understand what is going on with the patient and you are not told how you have to stay with the patient, I think that is a major challenge. I wish we could be given more time to be helped us as carers and how you are going to cope". (FGD R7)

Of note the majority of caregivers commented that it was the first time that they had been asked about how caring for their relatives was affecting them.

#### 4.4.6 Divine intervention

Some caregivers had become so helpless and did not know what to do anymore and were just waiting and hoping for a miracle from God to happen to the patient. Some participants believed that mental illness is caused by evil spirits and the church then serves as an organ for cleansing the evil spirits.

" It's difficult to say but I just want God to help him to get better and take his medication so that he can get a job and do something with his own hands". (R4)

"You forget to such an extent that I asked God to help me because you can end up being mentally disturbed yourself because of thinking too much about God to help you". (R2)

#### 4.4.7 Comfort and hope

Family members also expressed their wish to be given hope by the health professionals. They wished their anxieties could be allayed by simply having someone talking to them and re-assuring them that their relatives would get better.

" We want to be given hope just to say things will be better, things will be fine, don't worry too much there are people with such conditions that have gone back to work and some have gone back to work, hope, hope is important." (R3)



The caregivers also said that it was important for everyone to commemorate Mental Health Day and felt the whole month of October should be dedicated to mental health with people wearing a ribbon in the same way as for HIV/AIDS and breast cancer campaigns. This they thought would help to create awareness about mental illness, increase knowledge of the illness and thereby reduce stigma and discrimination.

#### **4.5 Shona Symptom Questionnaire Response rate**

All 31 participants (100%) completed all 14 items of the SSQ. The most commonly recorded positive response was on item 1 with 29(93.5%) of the respondents reporting having times in which they were thinking deeply or thinking about many things within the past week. Three (9.7%) of the respondents had suicidal ideation. A total of eleven participants were referred to the psychiatrist for further assessment and management. This number was inclusive of those participants who were suicidal, those who broke down during the interviews and those who scored 11 and above.

Table 4: SSQ Results

ITEM	Shona Symptom Questionnaire Items --In the past week.....	Response: Yes N (%)	Response: No N (%)
	Did you have times in which you were thinking deeply or thinking about many things?	29 (93.5%)	2 (6.5%)
	Did you find yourself sometimes failing to concentrate?)	21 (67.7%)	10 (32.3%)
	Did you lose your temper or get annoyed over trivial matters?	21(67.7%)	10 (32.3%)
	Did you have nightmares or bad dreams?	9 (29%)	22 (71%)
	Did you sometimes see or hear things, which others could not hear?	8 (25.8%)	23 (74.2%)
	Was your stomach aching?	19 (61.3%)	12(38.7%)
	Were you frightened by trivial things?	13 (41.9%)	18 (58.1%)
	Did you sometimes fail to sleep or lose sleep?	20 (64.5%)	11 (35.5%)
	Were there moments when you felt life was tough that you cried or wanted to cry?	25 (80.6%)	6 (19.4%)
	Did you feel run down or tired?	18 (58.1%)	13 (41.9%)
	Did you at times feel like committing suicide?	3 (9.7%)	28 (90.3%)
	Were you feeling unhappy with things you were doing each day?	19 (61.3%)	12 (38.7%)
	Was your work lagging behind?	24 (77.4%)	7(22.6%)
	Did you feel you had problems in deciding what to do?	24 (77.6%)	7 (22.6%)

Table 5: SSQ Scores of Participants (N=31).

CMD Risk Category	SSQ Score ranges	n (%)
Low risk	3- 7	10(32.3)
Moderate risk	8 – 10	11(35.4)
High Risk	11- 13	10 (32.3)

Ten participants (32.3%) were at a low risk of Common Mental Disorder (CMD) whilst 11 (35.4%) were at moderate risk and 10 (32.3%) were at high risk of severe of CMD giving a total of 21 (68 %) at risk of CMD. Three (9.7%) had suicidal ideation.

There was a significant positive association between gender and CMD ( $p= 0.023$ ) but otherwise no significant association with any other socio demographic variables. Six (28.6%) males were at risk of CMD whilst 15(48.4%) females were at risk of CMD.

# **CHAPTER 5**

## **DISCUSSION**

### **5.1 Summary of findings**

This qualitative study highlighted the impact, coping strategies and needs of individuals caring for mentally ill family members with bipolar affective disorder and schizophrenia in Harare, Zimbabwe. The results of the study revealed that the impact of mental illness on family members included physical, psychological/ emotional, financial and social domains. The physical impact included being assaulted by the patients and sustaining injuries and bodily responses such as hypertension. The respondents reported crying, thinking too much and fear of the patient as some of the psychological and emotional effects. Sixty eight percent (68%) of the respondents were at risk of CMD and 9.7% had suicidal ideation thus calling for urgent intervention. Financial problems such as spending money on the patient's treatment, damage to property and loss of time to generate income or grow own food also emerged as part of the impact of mental illness on caregivers.

The social impact that emerged included stigma which resulted in efforts to conceal the illness, blaming of women caregivers by the husbands or the family members and being accused of having brought the illness into the family. It is important to note that most of the caregivers (68%) were female and approximately one third (35.5%) of the caregivers were mothers of the patients. The caregivers also reported rejection by family members and more widely the society as well as suspicious as they thought that people were laughing at them because they had a mentally ill relative.

In order to cope with the illness, caregivers used both emotion-focused and problem-focused coping strategies. Examples of emotion-focused coping strategies used by the family members were avoidance, resorting to alcohol use and resignation. The other coping strategy that emerged from most participants was spiritual assistance from the church as

well as prophets and traditional healers. Some of the problem-focused coping strategies used by family members were seeking more information about the condition, talking positively with the patient, maintaining the patient's social interests as well as involving them in social activities like going to church with them.

Needs identified were mainly financial and included money for subsistence, medication and the need to start income generation projects. Family members also expressed the need for support groups and information about the illness in the form of written materials. They also discussed about their need to have more health worker support as well as training in care giving skills.

It is also important to note that the majority of caregivers expressed that it was the first time that they had been asked about how caring for their relatives was affecting them. This emphasizes their lack of health worker support. This finding is likely an indication of isolation or lack of support for the caregivers and they could have therefore thought this interview was their lifeline. It is possible that there was competition between the caregiver and the patient for attention from the health care personnel. Three participants broke down during the in depth interviews were referred to a psychiatrist for further assessment and management after the interviews as they insisted they wanted to continue with the interviews. Ten participants who had an SSQ score above 11 suggesting they were at risk of severe CMD were referred to a psychiatrist and the Crisis Support Centre for further assessment and management.

Despite having interviewed caregivers for both schizophrenia and bipolar affective disorder, data suggested that overall; the impact, coping and needs of caregivers of these patients were similar whether the patients had schizophrenia or bipolar affective disorder.

## **5.2 Implications of findings and their relationship to the literature**

In this study 67.7% of the participants were female and of these 35.5% were mothers. This supports the findings by Nasser- Hassan et al. (2011) in Egypt which revealed that most of the caregivers 75% were female. A qualitative study which comprised of 12 participants conducted by Mhaule & Ntswane (2009) in the Mpumalanga Province of South Africa that set to look at the experiences of caregivers of individuals suffering from schizophrenia in rural areas showed that 67% of the caregivers were female. This also supported the findings from a study on the demographic factors and clinical correlates of burden and distress in relatives of service users experiencing schizophrenia in Nigeria by Ukpong (2006) which found that there were more women caregivers than men. This was attributed to the fact that culturally men are usually the bread winners and are committed to work outside the home leaving the caring role to the women.

The role of women as caregivers is deeply rooted in cultural gender roles and traditional concepts of family life (DiGirolamo, 2008). For example, gender socialization within the Mexican culture expects that women's highest priority is taking care of their families, whilst they ignore their own health needs. Traditional gender roles assigned to women emphasize obedience, dependence, submissiveness and self sacrifice (DiGirolamo, 2008). Gender norms across the world expect women to bear the burden of caring for the ill. Many men believe that caring is "women's work" and that it is beneath them, that their role as breadwinners should exclude them from domestic chores (DiGirolamo, 2008). Women's care giving is accepted as the norm of many cultures (Chitayat, 2009).

The non-financial negative effects of care giving are emotional and physical and are alarming, and consistent with findings in other settings. In an analysis of health, stress, and coping among women caregivers in Australia, Christina Lee (2008) found that family care giving was associated with a high level of psychological stress and increased psychiatric

symptoms and illness, depression, back pain, headaches, and negative effects on the immune system resulting in increased viral illness. The documented effects of family care giving justify arguments for the need for intervention and a more equitable division of this difficult workload between genders (Christina Lee, 2007).

The results of this study showed that interventions including treatment and medication often focus on the patient and ignore their caregivers yet caring for mentally ill individuals has, in itself, the spiral effect of triggering common mental disorder among caregivers. The impact of caring for someone with mental illness has been found to increase the risk of mental ill health to the caregiver that can take the form of depression and emotional stress. As indicated in the findings from this study, the caring process can be very tiring especially when the patient has severe mental illness, and long-term care can be a major source of stress.

The findings of this study confirm those from numerous studies in Western countries which have shown that family care giving causes stress, depression and financial difficulties (Wancata et al., 2006; Awad & Voruganti, 2008). In this study, caregivers reported symptoms of common mental disorder including crying, losing appetite, thinking too much and resorting to alcohol. Thinking too much (*kufungisisa*) was also reported by participants in a study by Abas et al. (1995) in their Zimbabwean study on depression. This is a symptom which came up from the present study participants. The results from the SSQ showed that a total of 68% of the participants were at risk of CMD with 35.4% at risk of severe CMD, thus supporting the above findings. "Thinking too much" is a commonly reported symptom depicting depression in many African and non-Western societies (Okello & Ekhlad, 2006). Gender had a significant association with CMD in this study, despite the small sample size. The Shona Symptom Questionnaire results showed that 25 (80.5%) of the participants felt that life was not worth living, whilst 29 (93.5%) either cried or felt like crying.

Management of psychological distress among caregivers requires a multidisciplinary approach and consideration of the cultural context of the caregiver as well as the family member. There is an urgent need to come up with interventions for those caring for mental patients in resource-limited settings.

### 5.2.1 Interventions for Caregivers

Family interventions and support in the form of educating the family about the illness should be included in the existing scarce services in developing countries (Shibre et al., 2003) and this was highlighted by most respondents in this study. Psycho-education has shown to be effective for family support in schizophrenia in many settings (American Psychiatric Association, 2004). Psycho education can also be adapted to be culturally acceptable in Zimbabwe, and potentially other countries in sub-Saharan Africa. Psycho-education interventions use a systematic approach based on supportive and behavior therapy approaches with emphasis on the needs of the patient and the caregiver. The main focus of psycho-education is to increase the patient and caregiver knowledge about the illness, which results in better adjustment to the illness and improves communication and problem solving skills (Mangliano et al., 2000). Group education for caregivers has been shown to reduce relapses among schizophrenic patients thereby reducing burden on the caregivers (Stam & Cuijpers, 2001; Mueser et al., 2001; Cassidy et al., 2008). In these studies knowledge of schizophrenia correlated negatively with burden.

However, contrary to these findings was a randomized controlled trial in Malawi by Sefasi et al., (2007), which revealed that caregiver burden in schizophrenia correlated positively with knowledge about the condition which meant that the greater the knowledge of the condition, the greater the burden. This did not mean that knowledge caused the burden but the results were attributed to cultural factors. In the Malawian society, it is believed that those who have more knowledge of the condition sought the biomedical management of the patient and in



the process spent more money in the treatment of the condition resulting in burden (Sefasi et al., 2007).

Countries with limited resources need to make efforts to provide adequate care for their citizens with mental disabilities and their caregivers, a recommendation which was also made by Osayi et al (2010) following their study on caregiver burden in Midwest Nigeria. In Zimbabwe and most Sub-Saharan countries where there is limited medical insurance among the populations, the financial burden of caring for patients with mental illness is a responsibility of family members. This aspect was highlighted by most respondents in this study.

Health care workers need to pay more attention to the needs of the caregivers of patients with mental illness (Yusuf, 2009). It is important for them to provide information to the caregivers of people with mental illness as well as allocating more time to caregivers to discuss the conditions and counsel them. This recommendation was also made by Shibre et al (2003) in their cross-sectional study on caregiver burden in Ethiopia. Caregivers of patients with both bipolar affective disorder and schizophrenia have been found to require emotional support, psycho education and information about the illness for them to effectively provide care and support to their mentally ill relatives (Kupiers & Bebbington, 1995). The caregivers need a lot of support but the support they get from mental health professionals is not enough as highlighted by some of the participants in this study.

There is a need to increase the knowledge among health care workers about what the illness means to family members. This knowledge could help health care providers to have an in-depth understanding of what kind of support is required by caregivers. A study by Dixon et al. (2001) on the effectiveness of a family education programme in the USA revealed that families living with mentally ill relatives are inadequately understood by health professionals and emphasized the need to increase their knowledge about the experiences of the caregivers living with a mentally ill patient.

Another study by Jonsson et al. (2011) on the experience of living with a family member with bipolar disorder in Sweden revealed that family members felt left alone and that the way family members' experiences of the condition were recognised and valued by others affected the way they were coping with the illness. The way in which health professionals behave towards caregivers can be very stressful (Van der Voort et al., 2009). Nurses are the ones who are involved in the long term management of the patients with mental illness so they may be in a position to offer support to the caregivers as part of standard care in Zimbabwe.

A randomized control trial was conducted in Europe to examine the outcomes of a ten session educational intervention for families of patients with bipolar mood disorder. The study results showed that there was a significant improvement in stress management among caregivers and that social functioning was retained among the patients (Jonsson et al., 2010).

The findings of the present study also indicate that family members might benefit from seeking support from friends and family members or from establishing / attending a self help support group. Support groups provide an opportunity for caregivers to share their experiences with people who are facing the same challenges (Mental Health Association, 2004). Support groups provide a venue for affected family members to meet and share experiences as well as helping each other to cope better (Mittleman et al., 2006). Support of caregivers by others helps to alleviate stress especially if the supporter is considerate and empathetic (Haley et al., 2004).

There is also a need to include other household members and community members more widely to reduce the stigma, blame and rejection that caregivers (and patients) face in the community. Most women in this study reported being blamed for the illness which also resulted in them being rejected and stigmatized. It is not culturally uncommon in Africa for women to be blamed for all negative events in families. This may be attributed to lack of knowledge on the part of the family members on the causes of mental illness, a situation that

it is at least potentially possible to change and which may result in reduced stigma and discrimination against patients with mental illness as well as their caregivers.

Stigma associated with mental illness in families has many times resulted in strained relationships within the families themselves as well as difficult relationships with neighbours and the society at large (Struening et al., 2001). This has been attributed to the misunderstanding of mental illness aetiology (Shibre et al., 2001). Stigma has been found to be linked with depressive symptoms among families of patients with mental illness (Phelan et al., 1998; Perlick et al., 2001).

In the present study, talking to other caregivers with the same problems or friends was recommended by some participants and this is consistent with findings by Kartalova & Doherty (2008). This is an important consideration, but needs to take into account challenges of stigma in families and wider society (Gonzalez et al, 2007). From this study participants seemed to believe that stigma can be reduced if there is increased understanding of the illness as well as understanding of what the caregivers go through in caring for a mentally ill relative.

The study findings suggested that taking care of a mentally ill person drains available finances and also results in loss of time to generate income or to grow food. In this study 74% of the participants were unemployed and therefore had challenges in paying for the patient's medication as well as for the general upkeep of the patient. This supports a finding by Shibre et al. (2003) in Ethiopia that revealed that 74.4% of caregivers suffered financial burden and female relatives were affected more than males. It could also form a key to understanding the cycle of mental illness and poverty in households, and the crucial role of caregivers in this respect. Following the implementation of a community mental health programme by Basic Needs in rural Kenya, caregivers were able to take on income generating roles which were associated with significant increases in mean household income (Lund et al, 2013). This is a model that was designed to address the needs of people

living with mental illness in poor communities in low income countries (Basic Needs, 2008). The model is composed of five separate modules which all have to be implemented in order to realize its effectiveness. This model could similarly be introduced in Zimbabwe to ease the financial burden on caregivers of the mentally ill.

One potential intervention is that the Government could consider providing financial support, for example in the form of micro-credit schemes for the female caregivers to help them generate income to care for their mentally ill family members. Women tend to shoulder the greater burden of the welfare of the family and the children. They also have community and social obligations and engage in more than one economic activity as well as undertaking domestic chores (Pitamber, 2003). Micro-credit has shown several benefits as a poverty alleviation tool (Otero & Rhyne, 1994: Khandker, 1998). However, a survey done by Sunita Pitamber (2003) in Ethiopia and Malawi revealed that micro- credit schemes were not successful due to constraints women faced in gender roles, other socio- cultural barriers, and inadequate experience in credit management. Interest rates were also very high in these two countries and women ended up relying on their husbands' incomes for the repayments of the loans. If these challenges are looked into, then micro credit schemes could be effective in mitigating the financial constraints faced by caregivers of the mentally ill in Zimbabwe. Since these micro credit schemes have shown to be a challenge in sub-Saharan Africa (Pitamber, 1999: Buss, 1999: Campion, 2002), supported employment programmes for the patients could be helpful and these could be sustainable. A review by Bond (2004) of 9 randomized control trials and 4 other studies revealed that 40 to 60% of people with severe mental illness engaged in supported employment programmes compared to 20% not enrolled in a similar programme held competitive employment in high-income countries.

Finally, another intervention mentioned by study participants was provision of hope. In recognizing and embracing the value of hope in coping with adverse situations and managing the uncertainty inherent in many chronic illnesses' the nursing profession most

notably have been charged with responsibility to inspire and engender hope in patients (Vaillot, 1974; Jevne & Nekolaichuk, 2003). Kubler-Ross in her important work on Death and Dying (1970) strongly endorses hope; arguing that whilst perpetuating 'a glimpse of hope' may be a form of temporary denial this was necessary to engender meaning.

Mental health practitioners could be trained around imparting hope in caregivers as well as teaching caregivers appropriate coping skills. It is important for them to help caregivers enhance their coping strategies, support existing skills and facilitate the development of new ones. Findings by Jonsson et al (2011) revealed that hope was crucial for family members living with a family member with mental illness, a finding also supported by Bland & Darlington (2002). Health care workers should be aware of the importance of creating a positive attitude towards the caregivers as they go through the difficult situation of caring for their mentally ill family member. The findings of this study indicated that there seemed to be a competition between the caregivers and the patients for care and attention from the health care professionals.

### 5.2.2 Coping Strategies for caregivers

The caregivers used both problem focused and emotion focused coping strategies across both conditions. This supports the findings by Ganguly et al in (2010) in their qualitative study, the results which revealed that coping strategies were the same in caregivers of bipolar disorder and schizophrenia.

One coping strategy that emerged prominently was seeking spiritual assistance from different institutions. This is linked to the understanding of the etiology of mental illnesses. In this study people believe mental illness is caused by witchcraft, consistent with findings by Patel et al (1995) in their study on 'Explanatory Models of Mental illness in Sub-Saharan Africa'. However, they noted a diminishing concern with ancestral spirit beliefs among the educated urban population and this was also mentioned by participants in this study. This is

also supported by findings in an Ethiopian study by Shibre and Tefera (2012) on the perceived causes of severe mental illness and preferred interventions in Ethiopia. This revealed that the cause of mental illness was believed to be witchcraft and that prayer was one of the interventions mostly used to cope with the conditions. Most of the participants in this study were women who used prayer as a way of coping. This is consistent with findings from Ethiopia, where women were found to use religion or faith coping mechanisms more frequently than men (Shibre et al., 2003). The majority of participants 30 (96.6%) in this study belonged to a church. Although a belief in witchcraft and evil spirits still plays an important role as a cause of mental illness in Zimbabwe and Botswana, a number of biomedical models are being considered (Dale & Ben-Tovim, 1994).

The findings regarding seeking of spiritual assistance as a way of coping are important in the design of potential interventions to support caregivers. In this study some participants sought assistance from traditional healers first and the role of traditional healers, prophets, priests and pastors was considered to be very important. Interventions could therefore be designed to encourage traditional and other religious practitioners to refer patients to medical facilities. This could be included into the Zimbabwe National Mental Health Strategy, which should aim at appreciating the role of culture in mental illness as was done in Ethiopia. The element of traditional practitioners is acknowledged in the mental health strategy but the issue of referral of patients amongst them is still overlooked. The Ethiopian health policy states that "Due attention shall be given to the development of the beneficial aspects of traditional medicine including its gradual integration into modern medicine "(Ethiopia's Health Policy, 1983 p37). The findings of this study indicate that both traditional healers and biomedical healers can help mentally ill persons and their families. Plans could be made to integrate these services in Zimbabwe. It is not unusual in Africa, including Zimbabwe, for people to use both Western and Traditional forms of healing for mental illness (Okello & Neema, 2007).

### 5.2.3 Task shifting/ Task sharing

Pilot programmes in a few developing countries have demonstrated that provision of psychiatry services through the primary health care systems is feasible through training of primary health care personnel who are able to then provide public education and strengthen the families for home care (American Psychiatric Association, 2004). These can be used also to provide support to the caregivers and adequate financing of these should be ensured by the Government.

There is a critical shortage of psychiatry health professionals in Zimbabwe and as a result the available personnel do not have adequate time for the caregivers to give them support and health education. Those who are available are so overwhelmed by their work to an extent that they do not have the patience to give support to the caregivers but tend to concentrate on the patients only, though no research has been done yet to prove this. Task shifting may potentially be effective in alleviating this critical shortage of human resources in mental health. This refers to the delegation of tasks to cadres who are less trained or lay workers who can take up the responsibility of diagnosis and management of minor cases whilst the specialists take care of the serious conditions (Fulton et al, 2011). Adequate training and supervision of these non specialized cadres by psychiatrists, psychologists and mental health nurses is essential. Family caregivers can also be involved in detection of mental health disorders and encourage their relatives to go for treatment. A one month educational intervention conducted for family caregivers of children with schizophrenia in Iran showed that caregivers had better understanding of their children's' conditions and hence improved outcome (Assadollani et al., 2000). Social workers can also be involved in forming and facilitating support groups as well as offering psycho education for patients and their caregivers, as they are part of the multidisciplinary team (Srinivasa et al., 2005). This has been done successfully in India as well as in Chile and has shown to reduce caregiver burden (Srinivasa et al., 2005). Task shifting is potentially an effective and feasible approach

to improving human resources in mental health though it requires effective supervision and management as well as further research on its effectiveness (Srinivasa et al., 2005).

## **5.3 Strength and Limitations of this study**

### **5.3.1 Strengths**

The strength of this study is that it presents new knowledge on the views of family caregivers of the mentally ill, their coping strategies as well as their needs. This area has received very little prior research attention in Zimbabwe and Africa in general. Qualitative studies are important as they provide an opportunity to describe the lived experiences of participants and in this study lived experiences of care giving in bipolar affective disorder and schizophrenia were described. These qualitative studies can lay the foundation for further quantitative observational and intervention studies. This study also revealed that care giving is done mostly by women, an area that also needs to be explored in Zimbabwe.

The present study findings have generated hypotheses for more research to investigate the impact of mental illness on caregivers in other areas especially the rural areas of Zimbabwe. The study findings are also useful for policy formulation to re-design or resuscitate appropriate mental health intervention strategies for caregivers of the mentally ill in Zimbabwe.

### **5.3.2 Limitations of the study**

The results of the study can only be generalised to those caregivers attending Hospital and cannot be generalised to the entire Zimbabwean population as the study was exploratory. Participants were purposefully selected by the researcher and the views expressed by the participants interviewed in this study may not reflect the views of all the caregivers of mentally ill patients in Zimbabwe. The other limitation is that this study focused on the



caregivers of patients with severe mental illnesses of Schizophrenia and Bipolar Disorder and therefore cannot be generalised to caregivers of other mental illnesses.

The sample size for the quantitative aspect was also very small thereby further affecting generalisability of results and the potential statistical analysis that could be conducted. There was no comparison group for the SSQ results, making it difficult to establish the extent to which the high rates of CMD were associated with care giving or other factors such as genetic factors. There was a possibility of social desirability bias in which the participants may have given responses that they thought the researcher wanted to hear. This is because the researcher was known to some of the participants as she does clinical work in the same unit.

## **5.4 RECOMMENDATIONS**

From this study, it is evident that the effects of care giving in mental illness are similar to those of care givers in other parts of the world as supported by literature reviewed for this study. It is vital to address the needs of family caregivers in order to help them cope with the illness, provide adequate support to their mentally ill family member and prevent the occurrence of CMD among family caregivers. The recommendations that emanate from this study can be broken down into those pertaining to clinicians, policy makers, service managers, family members and researchers.

### **5.4.1. Clinicians**

There is a need for clinicians to provide adequate time to care givers to discuss their concerns. They should also ensure that the family members are educated about the different conditions so that they know how to manage the condition and how the symptoms manifest. There is also need for them to provide practical guidelines to caregivers on how they can deal with the symptoms. Clinicians need to work towards providing hope for the family members and it should be made clear to the doctors and nurses that they should address

the family concerns in addition to medication in their consultations. Psycho-education models that are culture sensitive need to be introduced as standard care for the patients and their families in order to help them cope with the illness.

#### 5.4.2 Policy makers and service managers

Service managers need to be aware that care giving by the families is not always possible. Though de-institutionalization is what is being encouraged presently, there is still need for establishment of long stay halfway homes for those patients that cannot be managed from home. Day care centers also need to be established where patients can be rehabilitated during the day and then go back to their families in the evenings. This could provide respite for the family members and give them an opportunity to be involved in income generation projects or go back to work. Service managers should also ensure availability of medicines at all institutions so that the relatives do not have to pay for the medication or travel long distances to get them.

Policy makers may need to consider partnership between the formal and informal health providers so that they are made aware of how, when and where to refer complex cases beyond their expertise. There is a need to include this in the Mental Health Act.

Community Health Services need to be revived as well as training of primary care workers on the management of psychiatry disorders. This can facilitate easy assistance to the caregivers at their settings within the community. Service providers should consider development of tailor made anti stigma initiatives that are culturally sensitive in order to help reduce stigma and discrimination among the community.

#### 5.4.3 Family Members

Family members and patients need to be encouraged to form support groups where they can offer guidance and support to each other on the care of the patients. Household

members and community members should be included more widely to address stigma, blame and rejection.

Awareness campaigns also need to be conducted by affected family members with the assistance of the Ministry of Health in order to reduce stigma and increase understanding of mental illness in the community. Among the most effective interventions for reducing stigma is personal contact with people with mental illness, and allowing them to share their experiences (Thornicroft et al., 2008). This can also be done in Zimbabwe to reduce stigma.

#### **5.4.4 Researchers**

Further research is required to assess CMD among a larger sample of caregivers as well as on caregivers of other psychiatric conditions. This can help to identify the magnitude of the problem and potential for early intervention.

Research should also be conducted to quantify the extent of the burden of care giving among caregivers of mentally ill patients in Zimbabwe.

Research also needs to be done to assess the burden of care among health care professionals and how they think they can help the caregivers to cope better.

Intervention studies with robust designs, such as randomized control trials need to be conducted to assess the effectiveness of psycho-education interventions for caregivers in the management of psychiatric patients in Zimbabwe.

### **5.5 Conclusion**

Relatives of patients with bipolar affective disorder and schizophrenia at Annexe Psychiatry Unit experience financial, psychological, physical and social challenges as well as stigma. Both emotion focused and problem focused coping strategies are used to cope with the illness and prayer is the most frequently used way of coping. There is need for health care professionals to give more attention to the caregivers in terms of offering psychological

support, family education and giving information about the condition. Policy makers need to come up with strategies to help families cope with the illness, including provision of financial support. Awareness campaigns are crucial in the prevention of stigma and discrimination against mental illness.

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## **Appendix A**

### **INFORMED CONSENT FORM**

**UNIVERSITY OF ZIMBABWE  
COLLEGE OF HEALTH SCIENCES  
DEPARTMENT OF PSYCHIATRY**

#### **PROJECT TITLE**

The perceived Impact of a Relative's Mental Illness on the Family Members, their Reported Coping Strategies and needs: A Zimbabwean Study

Principal Investigator:

Bazondlile Marimbe- Dube

Phone Numbers: (04)791631 ext 2268

Cell: 0772212837

What you should know about this research study:

We give you this consent form so that you may read about the purpose, risks, and benefits of this research study.

The main goal of this research is to gain knowledge that may help future patients and their families.

We cannot promise that this research will benefit you. Just like regular care, this research can have side effects that can be serious or minor.

You have the right to refuse to take part, or agree to take part now and change your mind later.

Whatever you decide, it will not affect your regular care. Routine care is based upon the best known treatment and is provided with the main goal of helping the individual patient.

Please review this consent form carefully. Ask any questions before you make a decision.

Your participation is voluntary.

#### **PURPOSE**

You are being asked to participate in a research study to find out about the challenges that you experience in caring for your mentally ill relative and how you have been coping with

them. I also would like to find out your views on how you can be helped to cope with your mentally ill relative. You were selected as a possible participant in this study because you have a mentally ill relative.

## PROCEDURES AND DURATION

I plan to collect information through a self administered questionnaire, interviews and group discussions. If you participate in a focus group discussion it will take about an hour. If you participate in the in depth interview it will take about 45 minutes. You will be asked about the challenges you face in caring for your ill relative, how you have been coping and how you would like to be assisted to cope better.

## RISKS AND DISCOMFORTS

The anticipated risks could be in the focus group discussions where participants will share confidential information. This risk will be kept to a minimum through ensuring confidentiality. Only the researcher, who is a trained mental health professional will have site of the identifying details of participants. All identifying details will be removed for further analysis or report writing. Questionnaires as well as the audio tapes will be kept in a lockable cupboard for the entire study period and only the researcher will have access to the keys. The information will be discarded after data has been analyzed and results disseminated. Any information that is obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission.

A second risk is that potentially upsetting issues will be discussed. To minimize this risk the interviews will be held in a supportive and non-judgmental manner by the researcher who is a mental health professional. Those participants observed to be in psychological distress will be referred by the researcher to the Psychiatrist on duty for assessment and management at no cost.

## BENEFITS AND/OR COMPENSATION

There are no anticipated financial costs and no rewards for the participants. To compensate for your time, you will on the study day not queue for your relative to be reviewed or admitted as well as for supply of medication which usually takes about two hours. The knowledge gained will be used to improve care of the mentally ill patients and their families, as well as improving your ways of coping.

## ADDITIONAL COSTS

No additional costs will be incurred by you if you decide to participate in this study.

## VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with the Parirenyatwa Annexed Psychiatry Unit, its personnel, and associated hospitals. There will be no reprimand, penalty or loss of any health benefits or any other benefits entitled to you and your mentally ill family member. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty.

## Audio Recording

Both focus group discussions and in-depth interviews will be audio taped and you will be allowed to listen to the recorded information if you wish to. The recordings will be used only for the study and will be discarded when the study is complete and results disseminated. No one will have access to the tapes except the researcher.

### Statement of Consent to be Audio taped

I understand that audio recording will be taken during the study. (Mark either "Yes" or "No")

I agree to be audio recorded

yes ☐

No ☐

### OFFER TO ANSWER QUESTIONS

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

### AUTHORIZATION

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.

.....

Name of Research Participant (please print)

Date

.....

Signature of Participant

Time

.....

Signature of Researcher

Date

.....

### YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Medical Research Council of Zimbabwe on telephone 791792 or 791193 or The Chairperson Faculty of Health Sciences Human Research Ethics Committee room E52- 24 old Groote Schuur Hospital Old Main Building, Observatory 7925. Cape Town South Africa: Tel+27 21 406 6492.



## Appendix B

Gwaro Rwemvumo

UNIVERSITY OF ZIMBABWE COLLEGE OF HEALTH SCIENCES

DEPARTMENT OF PSYCHIATRY

### PROJECT TITLE

The perceived Impact of a Relative's Mental Illness on the Family Members, their Reported Coping Strategies and Reported needs: A Zimbabwean Study

Principal Investigator:

Bazondlile Marimbe- Dube

Phone Numbers: (04)791631 ext 2268

Cell: 0772212837

Zvaunofanirwa kuziva nezvetsvakiridzo iyi:

Tinokupai gwaro rwemvumo kuitira kuti muverenge nezvamunogona kusangana nazvo nekukosha kwetsvakiridzo iyi.

Kubatsirwa pane zveutano kunoenderana nezvakakosha zvinozikanwa nezvekurapa. Saka chinhu chikuru ndechekuona kuti murwere abatsirikana chose. Donzo guru retsvakiridzo nderekuwana ruziwo rwekubatsira varwere panguva inotevera.

Hatikuvimbisei kuti tsvakiridzo iyi inogona kukubatsirai asi sekubatsirwa kunoitwa vanhu vese inogona kukubatsirai kana kusakubatsirai.

Mune mvumo yekupinda muchirongwa nekubuda pamunodira kana mashandura pfungwa dzenyu nekufamba kwenguva.

Pane zvamunenge masarudza hazvifanirwi kukanganisa kurapwa kwenyu kwemazuva ese.

Ndapota ongororai gwaro iri mubvunze mibvunzo musati masarudza zvamunoda.

Kupinda muchirongwa isarudzo yenyu.

### ZVATIRIKUZVIITIRA

Muri kukumbirwa kuti mupinde mutsvakiridzoyekuwongorora matambudziko amunosangana nawo semhuri pakuchengeta hama yenyu inorwara nepfungwa uyezve nzira dzamange

muchishandisa kuti mugone kugara naye zvakanaka. Zvekare ndinoda kunzwa zvamunofungawo kuti zvingakubatsirai kuti zviite nyore kuvachengeta zvakanaka. Masarudzwa kuti mupinde mutsvakiridzo iyi nokuti muri mumwe we hama dzinorarama nekuchengeta varwere vefungwa uyezve makore enyu anoenderana nevanhu vanodikanwa kuti vapinde mutsvakiridzo iyi. Tsakiridzo iyi ichaitwa kune vanhu vanogona kusvika mazana mana muno muZimbabwe.

#### ZVICHAITIWA NENGUVA YACHO

Mukatenda kupinda mutsvakiridzo iyi ndakatarisira kuti ndiwane ruzivo urwu pamibvunzo yamuchapindura mega, mibvunzo yamuchapindura pandinokubvunzai munhu umwe neumwe uyezve nemibvunzo yamuchapindura tirimugungano kana chikwata chehama dzevarwere vepfungwa. Kutawura nemi kuchanditorera maminetsi angangopfuura makumi mana nemashanu chete pamunhu kuzoti kutaura tirimu gungano kana chikwata zvichatitorera awa rimwe chete. Muchabvunzwa mayererano nematambudziko amunosangana nawo pakuchengeta hama yenyu inorwara nefungwa uyezve zvamunofunga kuti zvingakubatsirai kuti mugone kugara navo zvakanaka.

#### ZVINGAKUKANGANISAI KANA KUTOI ZVINOITA KUTI MUSAGADZIKANE

Mimwe yemibvunzo yatichabvunza inogona kukonzera kusagadzikana kwenyu asi muchapatsirikana nokuti achabvunza mibvunzo aneruzivo rokutawura mayererano nezvepfungwa saka anogona kutaura nemi kugadzirisa mifungo iyoyo.

#### ZVAMUNGAGONA KUWANA

Tsvakiridzo iyi ichabatsira imi sehama nevamwe vanenge vasangana nemadambudziko pakuchengeta hama dzinorwara nefungwa kuti vagone kumira pakubatsira hama. Hakuna zvimwe zvamuchapiwa pakupinda muchirongwa ichi.

#### KURAPWA NEKUTARISWA KWENYU NEHAMA YENYU

Hama yenyu ichagona kutariswa nekurapwa sezvanga zvagara zvichiitwa chero mukaramba kupinda muchirongwa.

#### KUCHENGETEDZWA KWEZVICHAWANIKWA

Ukaratidza kuda kwako kupinda mutsakiridzo nekusaina unobvumidwza kubuda muchirongwa chero nguva yaunenge wada usina anokumanikidza kana kuchisidzirwa. Zvese zvamuchatiudza zvichachengetedzwa munzvimbo dzakakiiwa. Hakuna mazita achanyorwa mumapepa emibvunzo asi kuchaiswa manyorwa emanamba chete. Zvese zvichawanikwa zvichaiswa pamwe chete.

#### MIMWE MIRIPO

Hapana muripo kana mari yaunobvisa kuti unge uri muchirongwa.

#### SARUDZO YAKO YEKUPINDA MUCHIRONGWA

Kupinda kwako muchirongwa isarudzo yako uyezve ukafunga kubuda muchirongwa hazvizokanganisi kurapwa kwako kuchipatara cheParirenyatwa kana kudyidzana kwako nevekuUniversity of Zimbabwe kana vashandi veikoko.

Kana une mibvunzo maererano nezvetsvakiridzo iyi ridzai runhare motaura na:

Bazondlile Marimbe Tel: 791631 ext 2268 Cell: 0772 212 837

University of Zimbabwe, CHS Department of Psychiatry P.O. Box A178 Avondale Harare.

Mibvunzo maererano nekodzero dzako mutsvakiridzo iyi shanyirai:

The National Coordinator

Medical Research Council of Zimbabwe

National institute of Health Research

Cnr Mazoe Street/Josiah Tongogara Avenue

Harare

Phone 791792, 791193: Cell 0772 433 166

#### KUBVUMA KWAKO

Kuti upinde kana kusapinda mutsvakiridzo iyi kusaina kwako kunoratidza kuti wanzwisisa zvese zviri mugwaro iri nekuti mibvunzo yako yese yapindurwa ukasarudza kupinda mutsvakiridzo.

Statement of Consent to be Audio taped

Ndinonzwisisa kuti kuchava neku recoda patsvagurutso iyi.. (Mark either “Yes” or “No”)

Ndinobvuma kuti mu recode

Yes

☐

No

☐

#### MAERERANO NEMIBVUNZO

Usati wasaina mibvunzo iyi sununguka kubvunza mibvunzo yese yaungada kubvunza maererano netsvakiridzo iyi. Unogona kutora nguva yako kuti unyatsonzwisisa nezvayo.

\_\_\_\_\_  
Nyorai zita renyu

\_\_\_\_\_  
Zuva

\_\_\_\_\_  
AM

\_\_\_\_\_  
Zita rehama yakakumirirai

\_\_\_\_\_  
Nguva PM

Hukama nemi

#### UCHAPIWA RIMWE REGWARO RAWASAINA KUTI UCHENGETE.

Kana uine mibvunzo maererano netsvakiridzo iyi isiri iyo yapindurwa nevaridzi vechirongwa kana mibvunzo maererano nekodzero dzako kana kufunga kuti hauna kubatwa zvakanaka uchida kutaura neumwe munhu asiri uyo wevari kuita tsvakiridzo iyi ridzai runhare ku Medical Research Council of Zimbabwe panamba dzinoti 791792 or 791193.

## Appendix C

Consent No. \_\_\_\_\_

My name is Bazondlile Marimbe. I am undertaking a Master of Philosophy Degree in Public Mental Health with the University of Cape Town. I am conducting research to find out the challenges that you experience in caring for your mentally ill relative.

May you please answer the following questions as truthful as possible? Remember that there is no identifying information on this questionnaire and none of the answers will be attributed to you.

In ndinonzi Bazondlile Marimbe. Ndiri mudzidzi pa Cape Town University apo pandirikuita zvidzidzo zve MPhil ye Public Mental Health. Pakudzidzauku pane tsvagiridzo yandinofanira kuita, chinangwa chiri chekuwongorora matambudziko amunosangana nawo semnhuri pakuchengeta hama yenyu inorwara nepfungwa.

Ndirikukumbira kuti mupindure mibvunzo inotevera muchokwadi menyu. Hapana mazita amunonyora papepa iri uyezve hakuna mhinduro ichanzi ndeyaningi.

### Socio-demographic Data

Age.....

Gender.....

Religion.....

Employment.....

Marital status.....

Occupation.....

Educational level.....

Relationship to patient.....

Place of residence.....

Questionnaire: The Shona Symptom Questionnaire (SSQ 14)

Musvondo rapfuura... (During the course of the last week...)

Pane pamaimboona muchinyanya kufungisisa kana kufunga zvakawanda here?

YES/NO

(did you have times in which you were thinking deeply or thinking about many things?)

YES/NO

Pane pamaimbotadza kuisa pfungwa pfungwa dzenyu pamwechete here? YES/NO

(did you find yourself sometimes failing to concentrate?)

Maimboshatirwa kana kuita hasha zvenhando here? YES/NO

(did you lose your temper or get annoyed over trivial matters?)

Makamborota hope dzinotyisa kana dzisina kunaka here? YES/NO

(did you have nightmares or bad dreams?)

Maimbowona kana kunzwa zvinhu zvangazvisingawonekwe kana kudzwika nevamwe here?

YES/NO

(did you sometimes see or hear things, which others could not hear?) YES/NO

Mudumbu menyu maimborwadza here? YES/NO

(was your stomach aching?)

Maimbovhundutswa nezvinhu zvisina maaturo here? YES/NO

(were you frightened by trivial things?)

Maimbotadza kurara kana kushaya hope here? YES/NO

(did you sometimes fail to sleep or lose sleep)

Maimbonzwa muchiomera neupenyu zvekuti maichema kana kuti makambonzwa kuda kuchema here? YES/NO

(were there moments when you felt life was tough that you cried or wanted to cry?)

Maimbonzwa kuneta here? YES/NO

(did you feel run down or tired?)

Pane pamaimboita pfungwa dzekuda kuzviuraya here? YES/NO

(did you at times feel like committing suicide?)

Mainzwa kusafara here munezvamaiita zuva nezuva here? YES/NO

(were you feeling unhappy with things you were doing each day?)

Basa renyu raive rave kusarira mushure here? YES/NO

(was your work lagging behind?)

Mainzwa zvichikuomerai here kuti muzive kuti moita zvipi?

YES/NO

(did you feel you had problems in deciding what to do?)

Total Score:

## Appendix D

### Interview Guide

The proposed areas of inquiry were derived from literature review findings.

Demographic data for the relative: Age, sex, marital status, employment status, relationship to the patient will be obtained initially.

### Proposed questions

What is the patients' occupation? Have they ever worked or not, how do they spend their time if they are not employed, what sort of things / activities they are interested in and any change in the way of carrying out activities since the illness began?

When did your family member's illness begin? How did it start and what triggered it?

How did the symptoms of the illness show themselves? How severe was it?

What did you think caused the illness at that time?

How did you handle the problem?

Did your relative have access to health services and if so where? When? And what was the outcome?

What did the Doctors say about the type of the illness?

Has your relative had any relapses? And if so when? How often? And why did they relapse?

May I know how your relative's illness has affected you and the family as a whole in terms of the following?

Income/ finances

Family interaction

Leisure time and social life of the family

How has the illness affected other family members in terms of their work and employment?

How has the illness affected the general health of family members, any signs of worthlessness, hopelessness, anxiety, guilt, loss, resentment, anger, frustration or fear?

Has there been any increase in service utilization for any upper respiratory tract infections, or any stress and violence within the family?

Has the illness had any effects on people outside the household like neighbours/ what is their perception of the illness/ any negative ideas/ stigma?

How do relatives get along with the patient and any change in relationships since the patient's illness?

14. Are you facing any difficulties in living with the patient?

#### Coping Strategies

The following questions were derived from literature review on coping strategies:

15. How have you managed to cope with the illness?

(Problem focused coping): This term will not be used during the interview

Did you seek for more information about the illness?

Do you talk positively with the patient?

Have you maintained your relative's social interests?

Have you physically avoided the patient?

Have you involved the patient in social activities?

(Emotion focused coping) This term will not be used during the interview

Have you resorted to drinking alcohol or taking any drugs of abuse to try and cope with the illness?

Have you colluded with the patient's maladaptive behavior such as agreeing with them when they say strange things or refuse medication?

Have you used avoidance such as avoiding contact with the patient?

Have you ever used coercion such as losing your temper, shouting at the patient or acted impulsively?

Have you used resignation such as passive acceptance of the situation or hoping for a miracle?



Other forms of coping

Have you sought spiritual help such as consulting a priest or praying for the patient?

Have you managed to maintain your own social interests such as going out, taking breaks or attending to other things to try and cope with the illness?

Have you discussed problems related to the patient with your friends or colleagues?

16. How do you think the health professionals or the Government can assist you in the care of your relative or on how to cope with the illness?

Has any of the clinical staff asked you about your experiences in caring for your relative and how you are coping?

Would you benefit from printed information about the illness or forming a support group?

Would you benefit from interacting with other relatives with the same predicament?

17. Is there anything else that you would like to tell me about the patient, yourself or family members which we have not covered?

Thank you very much.

## Appendix E

(Interview Guide: Zvemunogona kubvunzwa )

Makore ekuberekwa, Makaroorwa kana kuroora, munoshanda here?Hukama hwenyu nemurwere, kwamunogara?

Mibvunzo mayererano nehama inorwara

Murwere anemakore mangani?Akaroora kana kuroorwa here? Murwere anoshanda here kana kuti akamboshanda? Kana ayimboshanda akaregerereyi basa?Kana asingashande anoswera achiiteyi kumba? Zvii zvaanofarira kuita uyezve zvakachinja here kubva paakatanga kurwara?

Akatanga rinhi kusanzwa zvakanaka? Zvakatanga seyi ?

Zviratidzo zvipi zvakaita kuti mufungidzire kuti wanga a kurwara uyezve zvanga zvakakomba seyi?

Makafungidzira kuti chii chakakonzera urwere uhu?

Makayita seyi nedambudziko iri?

Makaendesa murwere kuchipatara here uyezve chipi? Arwara kwenguva yakareba seyi? uyezve zvakafamba seyi?

Vezveutano vakatsanangura here kuti hama yenyu inorwara nechirwere chinonzi chi?

Hama yenyu yakamborwara here futi mushure mekumboita zvakanaka? Kana zvirizo rini?, kangani? uyezve chii chakakonzera kuti arware zvekare mushure mokunge ambopora?

.Ngatikurukureyi mayererano nematambudziko amuri kusangana nawo semhuri kuburikidza nehurwere wehama yenyu.

Ngatikurukureyi nenhawu dzemari?

Kunzwisisana mukutaurirana semnhuri kwakamira seyi?

Ngatikurukureyi nenhawu dzekutandara kana kufara semhuri?

Ngatikurukureyinenhawu dzeutano hwako kana hwevamwe mumhuri?

Hurwere hwehama yenyu hwakukanganisayi seyi semhuri tichitarisa pakuyenda kwenyu kumabasa?

Hurwere hwakakanganisa hutano wemhuri here chirudzii? Kune vari kuzvitora sekuti havana basa, kana kusava netariro, kana vanonzwa vasina kugadzikana, kana kuzvipa mhosva, kurasikirwa, hashu, kana kutya?

Pane kuwedzera here kwakaita pakurapiwa kwezvirwere zvechikosoro/chipfuva kana kushungurudzika pfungwa kanamhirizhonga mumhuri?

Hurwere hwehama yenyu pane zvahwakakanganisa here kune vasiri vemhuri yenyu sevavakidzani venyu. Vanoona sei hurwere uhwu, huyezve vanomboita pfungwa dzekushora kana kutsaura murwere here?

13.Kuwirirana kwevehukama nemurwere kwakamira sei, uye pane zvakachinja here pakufambidzana/kuwirirana kubva zvaatanga kurwara?

14.Mune matambudziko amuri kusangana nawo here pakugara nemurwere?

Nzira dzekukunda nadzo

The following questions were derived from literature review on coping strategies:

Murikukwanisa here kugamuchira nekugarisana nehurwere?

(Problem focused coping) :This term will not be used during the interview

Makambotsvaka ruzivo here nezvehurwere uhwu ?

Munotaura zvakanaka nemurwere here?

Munoramba muchiterera kana kutevedzera zvido zvemurwere here?

Munomboitiza kana kusada kuona murwere here?

Munomboisa murwere here pazvirongwa zvekufara nemhuri?

(Emotion focused coping)This term will not be used during the interview

Makamboita zvekunwa doro here kana kutora zvinodhaka senzira yekugamuchira hurwere?

Makambobvumirana here nemurwere kuti aregere kutora mushonga kana kutenderana naye achitaura zvinhu mature.

Makamboshandisa zvekunzvenga-nzvenga kuti musaonane nemurwere here?

Makamboshandisa zvekumanikidza kana kushatirwa kwakanyanya, kana kupopotera murwere musingazvitarisire?

Makamboshandisa chiramwa here kana kungogamuchira hurwere muchitarisira minana?

Dzimwe nzira dzekukunda

Makambotsvaga rubatsiro rwemweya kuvafundisi rwakaita sekunamatiwa kwemurwere here?

Makambochengetedza here zvido zvenyu zvakaita sekuwadzana nevamwe kana kumbotora zororo; kana kuita zvimwe zvinhu senzira yekugamuchira nayo hurwere?

Makambokurukura matambudziko anoenderana numurwere neshamwari dzenyu kana vamunoshanda navo?

Zvemunofunga kuti zvingakubatsirai kuti mugone kugara zvakanaka hehama yenyu

15. Munofunga kuti vana mazvikokota vehutano kana hurumende ingakubatsirai sei mukuchengeta murwere.

16. Pane mumwe wevashandi vechipatara akambokubvunzai magariro enyu nemurwere uyekutimurikuzvigonasei?

17. Mungabatsirikana here nezvinyorwa maererano nehurwere kana kuumba zvikwata zvevanhu vane dambudziko serenyu?

18. Mungabatsirika here nekudyidzana nevamwe vane dambudziko rinenge renyu?

19. Pane zvimwe here zvamunoda kundiudza nezvemurwere, nezvenyu; kana zvemhuri zvatisina kukurukura nezvazvo?

Tatenda chaizvo.

## Appendix F

Focus Group discussion guide

Areas covered:

Impact of mental illness on the family

Let us talk about your experiences in living with a relative who is mentally ill?

How has it been like having a mentally ill relative?

How does your relative's illness affect you and your family?

Probes

Who is affected, what areas of life are affected and how are they affected?

Any effects on the following areas: Income/ finance, social life and leisure, health of family members, work and employment, education, stigma?

Is there any aspect of the illness which causes more inconvenience than others, can you describe it, how does it affect the family, who is affected, when is it likely to be a problem?

Probes for stigma:

Are there any negative comments or straining of relationships because of the illness with neighbours or the community at large?

Are you as family members by any chance being blamed for you relatives' illness?

B. Coping:

1. Generally how have you been coping with the illness of your relatives?

Probes

How have you managed to cope with the illness?

(Problem focused coping) This term is there to guide the researcher and will not be used during the interview

Did you seek for more information about the illness?

Do you talk positively with the patient?

Have you maintained your relative's social interests?

Have you physically avoided the patient?

Have you involved the patient in social activities?

(Emotion focused coping) This term is there to guide the researcher and will not be used during the interview

Let us discuss issues of alcohol and drug use as a way of coping.

Have you colluded with the patient's maladaptive behavior such as agreeing with them when they say strange things or refuse medication?

Have you used avoidance such as avoiding contact with the patient?

Have you ever used coercion such as losing your temper, shouting at the patient or acted impulsively?

Have you used resignation such as passive acceptance of the situation or hoping for a miracle?

Other forms of coping

Have you sought spiritual help such as consulting a priest or praying for the patient?

Have you managed to maintain your own social interests such as going out, taking breaks or attending to other things to try and cope with the illness?

Have you discussed problems related to the patient with your friends or colleagues?

2. How have you been involved in the care?

3. Have you ever asked for advice from relatives, friends or professionals?

4. Have you ever tried to work out what works better or made some changes in your daily activities.

5. Which aspects of your relative's illness are difficult to cope with? How do you deal with it? How effective was that strategy?

Reported Needs for services

What kind of support services would you need as family members to help you cope with living with a relative with a mental illness?

Has any of the clinical staff asked you on your experiences in caring for your relative and how you are coping? Have any of the mental health professionals ever given you advice about how you can cope better?

Probes

More information about the illness from professional

Assistance on coping styles, Support groups for relative of the mentally ill or for patients, Counseling, help from the government.

Are there any other suggestions that we may discuss.

Thank You All for your time.

## Appendix G

Focus Group Discussion Guide (Translated to Shona)

Zvinogona kubvunzwa:

Udzamu hwechirwere chepfungwa mumhuri

Zvakamira sei kuva nehama inorwara nepfungwa?

Hurwere uhu huri kukuitai seyi imi nemhuri?

Probes

Ndiani ari kubatikana, munobatikana nenzira dzipi muhupenyu hwenyu, uye munobatikana zvakadini?

Kune shanduko here mune zvinotevera: Mari; magariro enyu nenguva yekutandara; hutano hwemhuri; basa; muzvidziidzo, kusagamuchirika nevamwe nekuda kwehurwere.

Pane chikamu chehurwere uhu here chinoita kuti mubatikane zvakanyanya kukunda zvimwe zvikamu.

Probes for stigma:

Pane kutaura kusina kunaka kana kusawirirana nevavakidzani kana venharaunda yenyu kuburikidza nehurwere uhu here?

Imi semhuri pane pamakambopihwa mhosva here nekuda kwehurwere hwehama yenyu?

Nzira dzekukunda nadzo

Murikukwanisa here kugamuchira nekugarisana nehurwere?

(Problem focused coping) :This term will not be used during the interview

Makambotsvaka ruzivo here nezvehurwere uhwu?

Munotaura zvakanaka nemurwere here?

Munoramba muchiterera kana kutevedzera zvido zvemurwere here?

Munombotiza kana kusada kuona murwere here?

Munomboisa murwere here pazvirongwa zvekufara nemhuri?

(Emotion focused coping) This term will not be used during the interview

Makamboita zvekunwa doro here kana kutora zvinodhaka senzira yekugamuchira hurwere?

Makambobvumirana here nemurwere kuti aregere kutora mushonga kana kutenderana naye achitaura zvinhu mature.

Makamboshandisa zvekunzvenga-nzvenga kuti musaonane nemurwere here?

Makamboshandisa zvekumanikidza kana kushatirwa kwakanyanya, kana kupopotera murwere musingazvitarisire?

Makamboshandisa chiramwa here kana kungogamuchira hurwere muchitarisira minana?

Dzimwe nzira dzekukunda

Makambotsvaga rubatsiro rwemweya kuvafundisi rwakaita sekunamatiwa kwemurwere here?

Makambochengetedza here zvido zvenyu zvakaita sekuwadzana nevamwe kana kumbotora zororo; kana kuita zvimwe zvinhu senzira yekugamuchira nayo hurwere?

Makambokurukura matambudziko anoenderana numurwere neshamwari dzenyu kana vamunoshanda navo?

2. Maimbobatsirawo sei muhurwere uhu?

3. Makambobvunza mazano kubva kuhama, shamwari, kana vanamazvikokota?

Makamboedza kuona kuti chii chinoshanda zviri nani here kana kushandura mashandiro enyu emazuva ose?

5. Chikamu chipi chehurwere hwehama yenyu chakanyanya kukuomerai pakumuchengeta? Munozvifambisa sei? Zvinoshanda zvakadini?

Zvamungada kuti mubatsirwe nazvo

Ko munofunga kuti mungawane rubatsiro rwakaita sei kubva ku Hurumende pamwe chete nenyanzvi dzezveutano kuti zviite nyore kugamuchira nokuchengeta hama dzinorwara nepfungwa?

Ko pane here vashandi vezveutano vakambokubvunzai mayererano nezvamunosanganidzana nazvo mukuchengeta nekugamuchira hurwere uhu neruzivo



rwenyu pamusana pechirwere ichi? Vakambokupai mazano here ekuti murerukirwe pakugamuchira hurwere uhu here?

Probes

Munofunga kuti mungabatsirikana here nekuwana rairo yechirwere ichi kubvakumazvikokota vezveutano?

Mungabatsirikana here pamapepa akanyorwa kana kuti kubva muzvikwata zvinoyamura panyaya dzechirwere ichi kana kuhurumende?

Pane zvamungade kuwedzera here pamusana penyu, murwere kana kuti vame vemumhuri zvatisina kukurukura nezvazo.

Tinokutendayi zvikuru nenguva yenyu

Telephone: 791792/791193  
Telefax: (263) - 4 - 790715  
E-mail: [mrc.zimbabwe@yahoo.com](mailto:mrc.zimbabwe@yahoo.com)  
Website: <http://www.mrcz.org.zw>



Medical Research Council of Zimbabwe  
Josiah Tongogara / Mazoe Street  
P. O. Box CY 573  
Causeway  
Harare

#### APPROVAL LETTER

Ref: MRCZ/B/358

06 July, 2012

**Mrs Bazondile Marimbe**  
UZ Department of Psychiatry  
P.O Box A178  
Avondale  
**Harare**

**RE: The perceived impact of a relative's mental illness on the family members, their reported coping strategies and reported needs: A Zimbabwean Study.**

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents that were submitted to the MRCZ for review:

- a) Study Protocol
- b) Consent forms(English and Shona)
- c) Questionnaire(English and Shona)
- d) Curriculum Vitae

• **APPROVAL NUMBER**

: MRCZ/B/358

This number should be used on all correspondence, consent forms and documents as appropriate.

- **TYPE OF MEETING** : Expedited
- **EFFECTIVE APPROVAL DATE** : 06 July 2012
- **EXPIRATION DATE** : 05 July 2013

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices or website should be submitted three months before the expiration date for continuing review.

• **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ website.

• **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ website is required before implementing any changes in the Protocol (including changes in the consent documents).

• **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ website.

• **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on [mrc.zimbabwe@yahoo.com](mailto:mrc.zimbabwe@yahoo.com)

**Other**

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

MRCZ SECRETARIAT  
FOR CHAIRPERSON  
MEDICAL RESEARCH COUNCIL OF ZIMBABWE



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

UNIVERSITY OF CAPE TOWN



Faculty of Health Sciences  
Human Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main Building  
Observatory 7925  
Telephone [021] 406 6338 • Facsimile [021] 406 6411  
e-mail: shuretta.thomas@uct.ac.za

19 July 2012

**HREC REF: 262/2012**

**Ms B Marimbe**  
**c/o Prof C Lund**  
Psychiatry & Mental Health  
J-Block  
GSH

Dear Ms Marimbe

**PROJECT TITLE: THE PERCEIVED IMPACT OF A RELATIVE'S MENTAL ILLNESS ON THE FAMILY MEMBERS, THEIR REPORTED COPING STRATEGIES AND REPORTED NEEDS: A ZIMBABWEAN STUDY**

Thank you for responding to the issues raised by the Faculty of Health Sciences Human Research Ethics Committee in your email received 17<sup>th</sup> July 2012.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year till the 30<sup>th</sup> July 2013**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: [www.health.uct.ac.za/research/humanethics/forms](http://www.health.uct.ac.za/research/humanethics/forms))

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

**Please quote the HREC. REF in all your correspondence.**

Yours sincerely

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN ETHICS**  
Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

s.thomas

**UNIVERSITY OF ZIMBABWE**  
**COLLEGE OF HEALTH SCIENCES**

**FROM:** Acting Chairman, JREC

**DATE:** 21/06/12

**TO:** **Sr. B. Marimbe**  
Psychiatry Department

**EXT:** 2241/2242/2240

cc. Chairman, Psychiatry Department

**RE:** **THE PERCEIVED IMPACT OF A RELATIVE'S MENTAL ILLNESS ON  
THE FAMILY MEMBERS, THEIR REPORTED COPING STRATEGIES AND  
REPORTED NEEDS: A ZIMBABWEAN STUDY: JREC/156/12**

Thank you for your application with the above mentioned title seeking approval from the Joint Parirenyatwa Hospital and College of Health Sciences Research Ethics Committee (JREC). The Committee has carefully evaluated and discussed the material you supplied.

It was agreed that your application be approved as a research project which is ethically sound.

**Approval Date:** 21 June 2012

**Expiry Date:** 20 June 2013

Wishing you an enjoyable and fruitful research.

**Prof. R. Masanganise**